



END OF LIFE CARE BIBLIOGRAPHY October 2004

1: Ann Emerg Med. 2004 Jun;43(6):787-8.

Comment on:

Ann Emerg Med. 2003 Nov;42(5):665-80.

Ann Emerg Med. 2003 Nov;42(5):681-4.

Ann Emerg Med. 2003 Nov;42(5):685-8.

The smallpox vaccine and coronary artery disease: a personal perspective.

Lammert GR.

Publication Types:

Case Reports

Comment

Letter

PMID: 15259164 [PubMed - indexed for MEDLINE]

2: Ann Emerg Med. 2004 Jun;43(6):783, 791.

Images in emergency medicine. Generalized vaccinia.

Lemery J.

Department of Emergency Medicine, New York University/Bellevue Hospital, New York, NY, USA.

Publication Types:

Case Reports

PMID: 15159712 [PubMed - indexed for MEDLINE]

3: Arch Ophthalmol. 2004 Sep;122(9):1407; author reply 1407-8.

Comment on:

Arch Ophthalmol. 2003 May;121(5):715-9.

The ocular complications of smallpox and smallpox immunization.

**Library Program Office
Office of Information**
Veterans Health Administration

Smith JA, Casey CG, Tierney BC.

Publication Types:

Comment
Letter

PMID: 15364730 [PubMed - indexed for MEDLINE]

4: Clin Infect Dis. 2004 Jun 15;38(12):1749-53. Epub 2004 May 19.

Modified vaccinia Ankara: potential as an alternative smallpox vaccine.

McCurdy LH, Larkin BD, Martin JE, Graham BS.

Vaccine Research Center, National Institute of Allergy and Infectious Diseases,
National Institutes of Health, Bethesda, Maryland 20892-3017, USA.

Despite the declaration of smallpox eradication in 1980, the existence of variola stockpiles and the threat of bioterrorism demand that immunity to smallpox through vaccination be maintained. Although the currently available vaccine was used for the most successful medical intervention ever accomplished, it also is associated with side effects that are difficult to accept in a vaccine for a disease that has not been present for >25 years. Herein, we review alternative approaches to maintaining immunity to smallpox through vaccination with attenuated poxviruses, and we suggest modified vaccinia Ankara (MVA) as a leading candidate for an alternative smallpox vaccine.

PMID: 15227622 [PubMed - indexed for MEDLINE]

5: Hist Sci (Tokyo). 2004 Mar;13(3):164-75.

Western medicine, Korean government, and imperialism in late nineteenth-century Korea: The cases of the Choson government hospital and smallpox vaccination.

Shin DW.

Korea Advanced Institute of Science and Technology, 373-1 Guseong-dong,
Yuseong-gu, Daejeon 305-701, Republic of Korea.

Publication Types:

Biography
Historical Article

Personal Name as Subject:

Chi SY
Allen HN

PMID: 15212040 [PubMed - indexed for MEDLINE]

6: J Allergy Clin Immunol. 2004 Aug;114(2):454-6.

Latex allergens are not detectable in reconstituted smallpox vaccine or vaccine vial stoppers.

Poland G, Ovsyannikova IG, Jones RT, Yunginger JW.

Publication Types:
Letter

PMID: 15341028 [PubMed - indexed for MEDLINE]

7: J Am Coll Cardiol. 2004 Jul 7;44(1):201-5.

Incidence and follow-up of inflammatory cardiac complications after smallpox vaccination.

Eckart RE, Love SS, Atwood JE, Arness MK, Cassimatis DC, Campbell CL, Boyd SY, Murphy JG, Swerdlow DL, Collins LC, Riddle JR, Tornberg DN, Grabenstein JD, Engler RJ; Department of Defense Smallpox Vaccination Clinical Evaluation Team.

U.S. Army Medical Command, Brooke Army Medical Center, Fort Sam Houston, Texas
78234-6200, USA. Robert.Eckart@us.army.mil

OBJECTIVES: The purpose of this study was to assess the follow-up of patients with vaccinia-associated myocarditis. **BACKGROUND:** With the threat of biological warfare, the U.S. Department of Defense resumed a program for widespread smallpox vaccinations on December 13, 2002. One-year afterwards, there has been a significant increase in the occurrence of myocarditis and pericarditis among those vaccinated. **METHODS:** Cases were identified through sentinel reporting to military headquarters, systematic surveillance, and spontaneous reports. **RESULTS:** A total of 540,824 military personnel were vaccinated with a New York City Board of Health strain of vaccinia from December 2002 through December 2003. Of these, 67 developed myopericarditis at 10.4 +/- 3.6 days after vaccination. The ST-segment elevation was noted in 57%, mean troponin on admission was 11.3 +/- 22.7 ng/dl, and peak cardiac enzymes were noted within 8 h of presentation. On follow-up of 64 patients (96%) at a mean of 32 +/- 16 weeks, all patients had objective normalization of echocardiography, electrocardiography, laboratory testing, graded exercise testing, and functional status; 8 (13%) reported atypical, non-limiting persistent chest discomfort. **CONCLUSIONS:** Post-vaccinial myopericarditis should be considered in patients with chest pain within 30 days after smallpox vaccination. Normalization of echocardiography, electrocardiography, and treadmill testing is expected, and nearly all patients have resolution of chest pain on follow-up.

Publication Types:
Review
Review, Tutorial

PMID: 15234435 [PubMed - indexed for MEDLINE]

8: J Antimicrob Chemother. 2004 Jul;54(1):1-5. Epub 2004 May 26.

Antiviral prophylaxis of smallpox.

Bray M, Roy CJ.

Biodefense Clinical Research Branch, Office of Clinical Research, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, Maryland 20892, USA. mbray@niaid.nih.gov

Proof-of-concept studies suggest that current defences against smallpox could be strengthened by supplementing vaccination with antiviral drug prophylaxis, based on aerosolized or orally available forms of the long-acting medication cidofovir. Delivery of aerosolized cidofovir to mice results in its prolonged retention in respiratory tissues and protection against lethal intranasal or aerosol poxviral challenge. Although cidofovir itself is not orally available, the addition of an alkoxyalkanol ether side-chain allows it to be absorbed from the gastrointestinal tract. This also markedly increases its antiviral activity and lengthens its intracellular half-life from roughly 3 to 8-10 days. Oral treatment also protected mice against lethal poxviral challenge. These results suggest that a single aerosol dose of cidofovir (or an alkoxyalkanol-ether derivative) could provide prolonged protection against initiation of smallpox infection, whereas oral treatment could prevent both initiation of infection and internal dissemination of virus. Both approaches may avoid the nephrotoxicity that occasionally results from intravenous cidofovir therapy.

Publication Types:

Review

Review, Tutorial

PMID: 15163655 [PubMed - indexed for MEDLINE]

9: J Environ Health. 2004 Jun;66(10):41.

Report assesses tools for measuring smallpox readiness.

[No authors listed]

Publication Types:

News

PMID: 15216567 [PubMed - indexed for MEDLINE]

10: J Gen Intern Med. 2004 May;19(5 Pt 1):451-5.

Differential willingness to undergo smallpox vaccination among African-American and white individuals.

Micco E, Gurmankin AD, Armstrong K.

Department of Medicine, University of Pennsylvania School of Medicine, Philadelphia, PA 19104-6021, USA. ellyn@mail.med.upenn.edu

Library Program Office
Office of Information
Veterans Health Administration

OBJECTIVE: To examine potential disparities in willingness to be vaccinated against smallpox among different U.S. racial/ethnic groups. DESIGN: Cross-sectional survey using an experimental design to assess willingness to be vaccinated among African Americans compared to whites according to 2 strategies: a post-exposure "ring vaccination" method and a pre-exposure national vaccination program. SETTING: Philadelphia County district courthouse. PARTICIPANTS: Individuals awaiting jury duty. MEASUREMENTS: We included 2 scenarios representing these strategies in 2 otherwise identical questionnaires and randomly assigned them to participants. We compared responses by African Americans and whites. MAIN RESULTS: In the pre-exposure scenario, 66% of 190 participants were willing to get vaccinated against smallpox. In contrast, 84% of 200 participants were willing to get vaccinated in the post-exposure scenario ($P = .0001$). African Americans were less willing than whites to get vaccinated in the pre-exposure scenario (54% vs 77%; $P = .004$), but not in the post-exposure scenario (84% vs 88%; $P = .56$). In multivariate analyses, overall willingness to undergo vaccination was associated with vaccination strategy (odds ratio, 3.29; 95% confidence interval, 1.8 to 6.1). CONCLUSIONS: Racial disparity in willingness to get vaccinated varies by the characteristics of the vaccination program. Overall willingness was highest in the context of a post-exposure scenario. These results highlight the importance of considering social issues when constructing bioterror attack response plans that adequately address the needs of all of society's members.

PMID: 15109343 [PubMed - indexed for MEDLINE]

11: JAMA. 2004 Sep 8;292(10):1205-12.

Vaccination success rate and reaction profile with diluted and undiluted smallpox vaccine: a randomized controlled trial.

Talbot TR, Stapleton JT, Brady RC, Winokur PL, Bernstein DI, Germanson T, Yoder SM, Rock MT, Crowe JE Jr, Edwards KM.

Department of Medicine, Vanderbilt University School of Medicine, Nashville, TN 37232, USA.S

CONTEXT: Additional smallpox vaccine doses are needed to augment current US national stockpile. Aventis Pasteur smallpox vaccine (APSV), initially manufactured in the 1950s from the New York Board of Health vaccinia strain in a frozen preparation, appears as effective as lyophilized vaccine but the effectiveness of diluted doses of APSV is unclear. OBJECTIVE: To compare the vaccination success rate and the reaction profile of various APSV dilutions. DESIGN, SETTING, AND PARTICIPANTS: A double-blind, randomized controlled trial of 340 healthy vaccinia-naïve adults aged 18 to 32 years from 3 academic medical centers who were vaccinated with 1 of 3 strengths of APSV dilutions (undiluted, 1:5, and 1:10) between October 9, 2002, and February 24, 2003. Volunteers were followed up every 3 to 5 days until the vaccination site healed for bandage changes, vaccine response assessment, and adverse event evaluation, followed by 1- and 2-month clinic evaluations and 6-month telephone interview. MAIN OUTCOME MEASURES: Successful vaccination, defined by presence of a vesicle or pustule at the inoculation site 6 to 11 days postvaccination, and local and systemic reactions to vaccination. RESULTS: A total of 340 volunteers were vaccinated (vaccine dose: undiluted, $n = 113$; 1:5 dilution, $n = 114$; and 1:10 dilution, $n =$

113). Following vaccination, 99.4% (95% confidence interval [CI], 97.9%-99.9%) of all volunteers had successful vaccinations. Success rates did not differ between the dilution groups (undiluted, 100.0%; 95% CI, 96.8%-100.0%; 1:5 dilution, 98.2%; 95% CI, 93.8%-99.8%; 1:10 dilution, 100.0% 95% CI, 96.8%-100.0%; $P = .33$). Overall, 99.7% of volunteers reported at least 1 local symptom at the vaccination site, and 61.8% had axillary lymphadenopathy, 15.0% developed satellite lesions, and 7.6% developed a rash away from the vaccination site. Fever developed in 21.5%. No differences were noted in local or systemic reactions between the 3 dilution groups ($P > .05$ for each comparison). A total of 25% of volunteers missed scheduled duties due to vaccine-related symptoms. CONCLUSIONS: Even at diluted doses, APSV is an effective smallpox vaccine, allowing for expansion of the current stockpile. However, reactogenicity was not reduced with dilution of the vaccine and, as with other smallpox vaccines, may impair daily activities.

Publication Types:

Clinical Trial

Multicenter Study

Randomized Controlled Trial

PMID: 15353533 [PubMed - indexed for MEDLINE]

12: Mayo Clin Proc. 2004 Sep;79(9):1193-6.

Stevens-Johnson syndrome after immunization with smallpox, anthrax, and tetanus vaccines.

Chopra A, Drage LA, Hanson EM, Touchet NL.

Department of Internal Medicine, Mayo Clinic College of Medicine, Rochester, Minn 55905, USA.

A 19-year-old male military recruit developed erythema multiforme 20 days after receiving a triad of vaccinations: smallpox (vaccinia virus), anthrax, and tetanus. Over the course of a few days, the erythema multiforme evolved into Stevens-Johnson syndrome, associated with widespread bullae, stomatitis, conjunctivitis, and fever. After 7 days of conservative management, the patient's signs and symptoms improved. This case serves as a timely reminder of a severe and potentially life-threatening complication of smallpox vaccination.

Publication Types:

Case Reports

PMID: 15357044 [PubMed - indexed for MEDLINE]

13: Med Hist. 2004 Apr;48(2):199-228.

Variolation, vaccination and popular resistance in early colonial south India.

Brimnes N.

Department of History, Aarhus University, DK-8000 Aarhus C, Denmark.

Publication Types:
Historical Article

PMID: 15151104 [PubMed - indexed for MEDLINE]

14: Minn Med. 2004 May;87(5):34-9.

Smallpox in Saint Paul and Minneapolis, 1924-1925.

Nelson PD.

Publication Types:
Historical Article

PMID: 15191066 [PubMed - indexed for MEDLINE]

1: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):314-6.

Comment in:
Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):245.

Hospice: a medical student's perspective.

Brandt MT, Joyce JM.

Division of Oral and Maxillofacial Surgery, University of Kentucky, Lexington, Kentucky, USA.

PMID: 15315196 [PubMed - indexed for MEDLINE]

2: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):297-302.

Hospice pharmaceutical cost trends.

Nowels D, Kutner JS, Kassner C, Beehler C.

Department of Family Medicine, University of Colorado Health Sciences Center, Aurora, Colorado, USA.

Hospices are required to provide pharmaceuticals under the Medicare Hospice Benefit. Since there are no data describing these costs for hospice programs, this study analyzes data from a cross-sectional survey of 34 hospices concerning their pharmaceutical cost trends. Most respondents reported higher pharmaceutical-related costs between 1998 and 2002, but a significant minority reported that their costs had decreased. Pharmaceutical costs varied by patient setting, but long-acting opioids and continuous-infusion delivery systems were the two most significant contributors. A variety of mechanisms were employed to control drug costs.

PMID: 15315194 [PubMed - indexed for MEDLINE]

3: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):294-6.

Case study: when should the scope of care extend beyond the patient?

Carter G, Morris GM, Stolick M, Hentz P.

Rehabilitation Services, Providence Healthcare System, Centralia, Washington, USA.

Publication Types:
Case Reports

PMID: 15315193 [PubMed - indexed for MEDLINE]

4: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):289-93.

Estimating goodwill: an application of Pine's procedures for hospices.

Doka KJ, Pine V.

The Graduate School, The College of New Rochelle, New Rochelle, New York, USA.

Hospice care is a philosophy as well as a business. As a business, especially in the current healthcare environment, it is subject to many of the same forces that affect other businesses, such as acquisitions, sales, and mergers. Yet, estimating the value of a hospice is problematic, since its most valued asset (the reputation and goodwill that it has generated within the communities it serves) is intangible. This article explores the problem of assessing the value of a hospice, applying Pine's model for estimating goodwill in funeral service as a useful approach for hospices. The article offers assumptions for assessment and examples of suggested approaches.

PMID: 15315192 [PubMed - indexed for MEDLINE]

5: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):285-8.

Companion animals in palliative care: stories from the bedside.

Geisler AM.

University of California, San Francisco, San Francisco VA Medical Center, San Francisco, California, USA.

Research has shown that a companion animal or pet can help a person better cope with stressful life events, prevent loneliness, decrease depression, improve activities of daily living (ADLs), and increase social interactions. Pets in nursing homes have been associated with decreased psychotropic medication usage and a greater than 50 percent reduction in healthcare costs. Despite research in

other areas of healthcare, there is limited data concerning the use of companion animals in palliative care. This article presents an overview of companion-animal-associated medical research as well as patient stories that illustrate the roles of companion animals in end-of-life care.

Publication Types:

Review

Review, Tutorial

PMID: 15315191 [PubMed - indexed for MEDLINE]

6: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):275-84.

Association of admission date with cancer patient survival at a regional hospice: utility of a statistical process control analysis.

Mertens WC, Hoople NE, Rodrigues C, Lindenauer PK, Benjamin EM.

Cancer Services, Division of Hematology/Oncology, Baystate Medical Center and Tufts University, Boston, Massachusetts, USA.

Previously published multivariate analyses have not considered date of entry as a possible factor associated with length of stay (LOS), nor has the pattern of decreasing LOS been analyzed. We set out to assess mean LOS over time and to determine the factors, including date of death, which are independently associated with LOS. Cancer patients admitted to our hospice from 1996 through 2001 were assessed for dates of admission/discharge/death, age, gender race, specific cancer diagnosis, referring physician characteristics, place of death, and health insurance type. Statistical process control (SPC) charts and proportional hazard models were constructed for patients prioritized by date of admission, with active or discharged patients censored. A total of 2126 patients were analyzed. An abrupt and significant drop in mean LOS was seen for all cancer patients and for most cancer sites from April to December 1998 (temporally associated with a "Special Fraud Alert" issued by the Office of Inspector General) and again in the second and third quarter of 2000. A proportional hazards model revealed that LOS was associated with cancer site ($p < 0.0001$), quarter in which patient was admitted ($p = 0.0020$), and sex (women surviving longer, $p = 0.013$), age (older patients surviving longer, $p = 0.0149$), and insurance ($p = 0.071$). Mean LOS is associated with date of admission to hospice independent of other associated factors. LOS decreases do not occur in a gradual, continuous fashion but suddenly and intermittently, and they are not associated with changes in referral numbers or readmissions. SPC charts proved to be an effective method of tracking and evaluating hospice LOS on an ongoing basis.

PMID: 15315190 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):267-74.

Measuring preparedness to address patient preferences at the end of life.

Kane MN, Hamlin ER 2nd, Hawkins WE.

Library Program Office
Office of Information
Veterans Health Administration

School of Social Work, Florida Atlantic University, Boca Raton, Florida, USA.

This study investigated the factor structure of an instrument to measure preparedness perception among Florida licensed clinical social workers for work with elders 'end-of-life care. In a principle component analysis with varimax rotation, three factors were identified with eigenvalues greater than 1.0 and a cumulative variance of 66.982 percent. These factors include: 1) knowledge of end-of-life care, 2) knowledge of resources for elders, and 3) attitude toward elder assisted suicide. The development of this type of instrument may be useful for future research and for determining future educational needs of social workers and other professionals.

PMID: 15315189 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):255-60.

The use of music in facilitating emotional expression in the terminally ill.

Clements-Cortes A.

Baycrest Centre for Geriatric Care, Department of Therapeutic Recreation, Toronto, Ontario, Canada.

The expression and discussion of feelings of loss and grief can be very difficult for terminally ill patients. Expressing their emotions can help these patients experience a more relaxed and comfortable state. This paper discusses the role of music therapy in palliative care and the function music plays in accessing emotion. It also describes techniques used in assisting clients to express their thoughts and feelings. Case examples of three in-patient palliative care clients at Baycrest Centre for Geriatric Care are presented. The goals set for these patients were to decrease depressive symptoms and social isolation, increase communication and self-expression, stimulate reminiscence and life review, and enhance relaxation. The clients were all successful in reaching their individual goals.

Publication Types:
Case Reports

PMID: 15315187 [PubMed - indexed for MEDLINE]

9: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):254.

Autonomy, advance directives, and artificial nutrition and hydration.

Rousseau P.

Publication Types:
Letter

PMID: 15315186 [PubMed - indexed for MEDLINE]

10: Am J Hosp Palliat Care. 2004 Jul-Aug; 21(4): 253.

Comment on:

Am J Hosp Palliat Care. 2004 Mar-Apr; 21(2): 116-20.

Subjectively interpreting the "good death".

Alexander L.

Publication Types:

Comment

Letter

PMID: 15315184 [PubMed - indexed for MEDLINE]

11: Am J Hosp Palliat Care. 2004 Jul-Aug; 21(4): 247-8.

Physician orders for scope of treatment: an idea whose time has come.

Baumrucker SJ.

Palliative Care Service, Wellmont Health Systems, Rogersville, Tennessee, USA.

PMID: 15315183 [PubMed - indexed for MEDLINE]

12: Am J Hosp Palliat Care. 2004 Jul-Aug; 21(4): 245.

Comment on:

Am J Hosp Palliat Care. 2004 Jul-Aug; 21(4): 314-6.

Medical education, hospice, and choices.

Enck RE.

Publication Types:

Comment

Editorial

PMID: 15315182 [PubMed - indexed for MEDLINE]

13: Am J Respir Crit Care Med. 2004 Aug 15; 170(4): 456-65.

Respiratory care of the patient with Duchenne muscular dystrophy: ATS consensus statement.

Finder JD, Birnkrant D, Carl J, Farber HJ, Gozal D, Iannaccone ST, Kovesi T, Kravitz RM, Panitch H, Schramm C, Schroth M, Sharma G, Sievers L, Silvestri JM, Sterni L; American Thoracic Society.

American Thoracic Society, USA.

Publication Types:

Consensus Development Conference
Guideline
Practice Guideline
Review

PMID: 15302625 [PubMed - indexed for MEDLINE]

14: Ann R Coll Physicians Surg Can. 2002 Jun;35(4):246; author's reply 246.

Comment on:

Ann R Coll Physicians Surg Can. 2002 Mar;35(2):107-8.

Quality end-of-life care.

Dunn RW.

FRCSC, Surrey, B.C.

Publication Types:

Comment
Letter

PMID: 14982088 [PubMed - indexed for MEDLINE]

15: Ann R Coll Physicians Surg Can. 2002 Jun;35(4):245; author's reply p.245-6.

Comment on:

Ann R Coll Physicians Surg Can. 2002 Mar;35(2):107-8.

Quality end-of-life care.

Skrinskas G.

FRCPC, North York, Ontario, Canada.

Publication Types:

Comment
Letter

PMID: 14982087 [PubMed - indexed for MEDLINE]

16: Ann R Coll Physicians Surg Can. 2002 Jun;35(4):225-231.

Routine advance directive and organ donation questioning on admission to hospital.

Essebag V, Cantarovich M, Crelinsten G.

McGill University Health Centre, 3600 Parc Ave. #1203, Montreal QC H2X 3R2, Canada. esseb97@med.mcgill.ca

Objective: The purpose of this study is to determine whether routine questioning on admission to hospital can identify patients who do not want cardiopulmonary resuscitation (CPR) or intensive-care unit (ICU) admission. We also determined whether routine questioning can identify patients interested in organ donation. Finally, we determined whether routine questioning helps train housestaff to discuss end-of-life issues with patients. **Methods:** The housestaff of an internal-medicine ward questioned admitted patients about previous discussions regarding resuscitation or organ donation, and about preferences regarding CPR, ICU, and organ donation. **Results:** Of 40 patients who had never discussed CPR and ICU issues, 25 per cent preferred no CPR, and 18 per cent preferred no ICU. Of 24 patients who had never discussed organ-donation issues, 67 per cent were interested in being donors. All housestaff felt more comfortable discussing end-of-life issues by the end of the study. **Conclusion:** Routine questioning of patients on admission identifies a significant number who prefer no CPR or ICU. This information may help to avoid inappropriate resuscitation efforts and ICU admissions. Routine questioning also reveals many patients who are interested in organ donation. Encouraging these patients to identify themselves and to discuss their wishes with family members may increase the number of procurable organs. Housestaff benefit from the experience of discussing end-of-life issues.

PMID: 14982085 [PubMed - indexed for MEDLINE]

17: BMJ. 2004 Aug 28;329(7464):515.

Comment on:

BMJ. 2004 Aug 7;329(7461):309.

Man wins battle to keep receiving life support: pro-choice living wills are essential.

Irwin MH.

Publication Types:

Comment

Letter

PMID: 15331491 [PubMed - indexed for MEDLINE]

18: BMJ. 2004 Aug 28;329(7464):491-4.

Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study.

Monteleoni C, Clark E.

Lenox Hill Hospital, 100 East 77th Street, New York, New York 10021, USA.
cmonteleoni@lenoxhill.net

Library Program Office
Office of Information
Veterans Health Administration

PROBLEM: Despite lack of evidence that enteral feeding tubes benefit patients with dementia, and often contrary to the wishes of patient and family, patients with dementia who have difficulty swallowing or reduced food intake often receive feeding tubes when hospitalised for an acute illness. DESIGN: We conducted a retrospective chart review of all patients receiving percutaneous endoscopic gastrostomy or jejunostomy tubes between March and September 2002.

QI

interventions including a palliative care consulting service and educational programmes were instituted. We conducted a second chart review for all patients receiving feeding tubes between March and September 2003. SETTING: 652 bed urban

acute care hospital. KEY MEASURES FOR IMPROVEMENT: We measured the number of

feeding tubes placed in patients with dementia, the number of feeding tubes placed in patients with dementia capable of taking food by mouth, and the number of feeding tubes placed in patients with dementia with an advance directive stating the wish to forgo artificial nutrition and hydration. STRATEGIES FOR CHANGE: Medical and allied health staff received educational programmes on end of life care and on feeding management of patients with dementia. A palliative care consulting team was established. EFFECTS OF CHANGE: After the interventions, the number of feeding tubes placed in all patients and in patients with dementia was greatly reduced. LESSONS LEARNT: Multidisciplinary involvement, including participation by the administration, was essential to effect change in practice. The intensive focus on a particular issue and rapid change led to "culture shift" within the hospital community. The need to establish unified goals of care for each patient was highlighted. BACKGROUND: A growing body of research over the past decade has questioned the utility of placing feeding tubes (percutaneous endoscopic gastrostomy (PEG) or jejunostomy) in patients with advanced dementia. Studies have found no evidence that feeding tubes in this population prevent aspiration, prolong life, improve overall function, or reduce pressure sores. Additionally, the quality of life of a patient with advanced dementia can be adversely affected when a feeding tube is inserted. The patient may require wrist restraints to prevent pulling on the tube or may develop cellulitis at the gastrostomy site, develop decubitus ulcers, be deprived of the social interaction and pleasure surrounding meals, and require placement in a nursing home. Unfortunately, many doctors are unfamiliar with this literature or face barriers-attitudinal, institutional, or imposed by the healthcare industry-to applying its findings to their practice. Thus feeding tubes are placed in patients who will not benefit from this intervention and whose quality of life in the terminal stage of their illness will be adversely affected. With the expected increase of elderly people with dementia, a great change in doctors' knowledge, attitudes, and practice is necessary to prevent even greater numbers of patients receiving this futile treatment.

PMID: 15331474 [PubMed - indexed for MEDLINE]

19: Brain Inj. 2004 Sep;18(9):935-40.

Further recovery in a potential treatment withdrawal case 10 years after brain injury.

McMillan TM, Herbert CM.

Psychological Medicine, University of Glasgow, Gartnavel Royal Hospital,
Glasgow, UK. t.m.mcmillan@clinmed.gla.ac.uk

A young woman was rendered tetraplegic and anarthric as a result of a traumatic brain injury in 1993. Two years later, she was considered to be in a minimally conscious state and became the subject of legal debate in the UK with regard to withdrawal of artificial feeding and hydration. Before injury, she made a verbal advanced directive that she would not wish to continue living if ever becoming severely disabled. Neuropsychological assessment found statistically significant evidence for sentience and expression of a wish to live and the application to Court was withdrawn. Further meaningful recovery occurred between 7-10 years after injury. She now lives in the community with 24 hour care. She speaks, initiates conversation and actions, expresses clear and consistent preferences and has a spontaneous sense of humour. She uses an electric wheelchair, eats solid food and drinks through a straw. Her mood is variable and sometimes low. This case demonstrates the need for careful consideration of advanced directives and for specialist neuropsychological assessment in people with severe cognitive and communication difficulties. It supports the view that routine assessment and follow-up of people thought to be in minimally conscious states is important. In addition, it shows that recovery with reduction in disability and significant implications for quality of life can continue for at least 10 years after extremely severe traumatic brain injury. Copyright 2004 Taylor and Francis Ltd

Publication Types:
Case Reports

PMID: 15223745 [PubMed - indexed for MEDLINE]

20: Can J Anaesth. 2004 Jun-Jul;51(6):631-6.

Simple changes can improve conduct of end-of-life care in the intensive care unit.

Hall RI, Rocker GM, Murray D.

Department of Anesthesia, Dalhousie University, and the Intensive Care Services, Canada.

PURPOSE: To describe changes to the conduct of withdrawal of life support (WOLS) in two teaching hospital tertiary care medical surgical intensive care units (ICUs) in a single centre over two distinct time periods. **METHODS:** We used a retrospective chart review with a before and after comparison. We assessed aspects of end-of-life care for ICU patients dying after a WOLS before and after we introduced instruments to clarify do not resuscitate (DNR) orders and to standardize the WOLS process, sought family input into the conduct of end-of-life care, and modified physicians' orders regarding use of analgesia and sedation. **RESULTS:** One hundred thirty-eight patients died following life support withdrawal in the ICUs between July 1996 and June 1997 (PRE) and 168 patients died after a WOLS between May 1998 and April 1999 (POST). Time from ICU admission to WOLS (mean +/- SD) was shorter in the POST period (191 +/- 260 hr PRE vs 135 +/- 205 hr POST, P = 0.05). Fewer patients in the POST group received cardiopulmonary resuscitation in the 12-hr interval prior to death (PRE = 7; POST = 0; P < 0.05). Fewer comfort medications were used (PRE: 1.7 +/- 1.0 vs

POST: 1.4 +/- 1.0; P < 0.05). Median cumulative dose of diazepam (PRE: 20.0 vs POST: 10.0 mg; P < 0.05) decreased. Documented involvement of physicians in WOLS

discussions was unchanged but increased for pastoral care (PRE: 10/138 vs POST: 120/168 cases; P < 0.05). The majority of nurses (80%) felt that the DNR and WOLS checklists led to improved process around WOLS. CONCLUSION: Simple changes

to the process of WOLS can improve conduct of end-of-life care in the ICU.

PMID: 15197128 [PubMed - indexed for MEDLINE]

21: Can J Anaesth. 2004 Jun-Jul;51(6):623-30.

Most critically ill patients are perceived to die in comfort during withdrawal of life support: a Canadian multicentre study.

Rocker GM, Heyland DK, Cook DJ, Dodek PM, Kutsogiannis DJ, O'Callaghan CJ.

Department of Medicine, Queen Elizabeth II Health Sciences Center, Halifax, Nova Scotia, Canada. gmrocker@dal.ca

PURPOSE: Most deaths in intensive care units (ICUs) follow a withdrawal of life support (LS). Evaluation of this process including the related perspectives of grieving family members is integral to improvement of palliation in the ICU. METHODS: A prospective, multicentre, cohort study in six Canadian university-affiliated ICUs included 206 ICU patients (length of stay ≥ 48 hr) who received mechanical ventilation (MV) before LS withdrawal. We recorded modes, sequence and time course of LS withdrawal and drug usage (4 hr before; 4-8 hr and 8-12 hr before death). We asked a specified family member to assess patient comfort and key aspects of end-of life care. RESULTS: MV was withdrawn from 155/206 (75.2%) patients; 97/155 (62.6%) died after extubation and 58/155 (37.4%) died with an airway in place. The most frequently used drugs and the cumulative doses [median (range)] in the four hours before death were: morphine 119/206, 24 mg, (2-450 mg); midazolam 45/206, 24 mg, (2-380 mg); and lorazepam 35/206, 4 mg, (1-80 mg). These doses did not differ among the three time periods before death. Of 196 responses from family members most indicated that patients were perceived to be either totally (73, 37.2%), very (48, 24.5%), or mostly comfortable (58, 29.6%). Times to death, morphine use and family members' perceptions of comfort were similar for each type of change to MV. CONCLUSIONS: Most patients were perceived by family members to die in comfort during a withdrawal of LS. Perceptions of patient comfort and drug use in the hours before death were not associated with the mode or sequence of withdrawal of LS, or the time to death.

Publication Types:

Clinical Trial

Multicenter Study

PMID: 15197127 [PubMed - indexed for MEDLINE]

22: Can J Psychiatry. 2004 Jun;49(6):366-72.

Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality.

Breitbart W, Gibson C, Poppito SR, Berg A.

Psychiatry Service, Memorial Sloan-Kettering Cancer Center, New York, NY 10021, USA. Breitbart@mskcc.org

Medical and psychological discourse on end-of-life care has steadily shifted over the years from focusing primarily on symptom control and pain management to incorporating more person-centred approaches to patient care. Such approaches underscore the significance of spirituality and meaning making as important resources for coping with emotional and existential suffering as one nears death. Though existential themes are omnipresent in end-of-life care, little has been written about their foundations or import for palliative care practitioners and patients in need. In this article, we explore the existential foundations of meaning and spirituality in light of terminal illness and palliative care. We discuss existential themes in terms of patients' awareness of death and search for meaning and practitioners' promotion of personal agency and responsibility as patients face life-and-death issues. Viktor Frankl's existential logotherapy is discussed in light of emerging psychotherapeutic interventions. Meaning-centred group therapy is one such novel modality that has successfully integrated themes of meaning and spirituality into end-of-life care. We further explore spiritual and existential themes through this meaning-oriented approach that encourages dying patients to find meaning and purpose in living until their death.

PMID: 15283531 [PubMed - indexed for MEDLINE]

23: Cancer Nurs. 2004 Jul-Aug;27(4):314-9.

End-of-life challenges: honoring autonomy.

Valente SM.

Department of Veterans Affairs and the University of Southern California, Los Angeles, CA, USA. sharon.valente@med.va.gov

Patients' end-of-life decisions challenge nurses to improve palliative care, symptom management, and patient advocacy, and examine ethical issues. When terminally ill patients take charge of the last stages of life, they may challenge nurses to reexamine attitudes about lifesaving technology and autonomy and values about preserving life. Staff members can become benevolent and believe that they know what is best despite the patient's independent decisions. When patients unsuccessfully decline continued aggressive, life prolonging strategies, they may decide to hasten dying rather than accept a natural death. Researchers (Breitbart WS et al. JAMA. 2000;284:2907-2911) defined desire for hastened death as a unifying construct underlying requests for assisted suicide, euthanasia, and withdrawal of food and fluids. When a terminally ill patient considers a hastened death, the nurse needs to examine the patient's mental health, symptom management, advance directives, and decision making. Medical and psychological symptoms and spiritual distress often trigger thoughts of

hastening death even when pain and symptoms have been treated (Breitbart WS et al. JAMA. 2000;284:2907-2911). Ethical issues and guidelines for management of patients and evaluation of rationality are presented.

Publication Types:

Case Reports

Review

Review, Tutorial

PMID: 15292727 [PubMed - indexed for MEDLINE]

24: Cancer Nurs. 2003 Jun;26(3):245-51.

When death is imminent: where terminally ill patients with cancer prefer to die and why.

Tang ST.

National Yang-Ming University, School of Nursing, #155, Sec. 2 Li-Nong Street, Taipei, Taiwan, Republic of China. stang@ym.edu.tw

End-of-life care strives to honor terminally ill patients' preferences regarding the way of dying. Scholars defined one domain of quality of dying and death as dying at the place of one's choice. Despite efforts over more than two decades and more than 40 studies to investigate the influencing factors associated with the place of death for terminally ill patients with cancer, there is a notable lack of empirical data examining the reasons why terminally ill patients with cancer choose a specific setting as their preferred place of death. An exploratory and descriptive study was conducted to explore the preferences of terminally ill patients with cancer for the place of death, to identify the reasons for selecting a preferred place of death, and to examine the importance of dying at a place one prefers. A convenience sample of 180 terminally ill patients with cancer was recruited from four tertiary care hospitals and two home care programs in Connecticut. Nearly 90% of the subjects preferred to die at home. Quality of life, availability and ability of family caregivers, concerns of being a burden to others, long-standing relationships with healthcare providers, and quality of healthcare were the major considerations in decision making regarding the place of death. Terminally ill patients with cancer acknowledged dying at their preferred place of death as highly important. Effective nursing interventions need developing to facilitate death at a place that is in accord with dying patients' preferences.

PMID: 12832958 [PubMed - indexed for MEDLINE]

25: Caring. 2004 Jun;23(6):26-9.

Collaborative pharmacy practice enters hospice care.

Knowlton CH.

excellerx, Philadelphia, USA. calvin@excellerx.com

PMID: 15270325 [PubMed - indexed for MEDLINE]

26: Caring. 2004 Jun;23(6):20-3.

Palliative care in home care: a model for practice.

Friedman J, Bono-Snell B.

St. Joseph's Hospital Health Center Certified Home Care Agency, Liverpool, New York, USA. Judith.friedman@SJHSYR.org

PMID: 15270324 [PubMed - indexed for MEDLINE]

27: Caring. 2004 Aug;23(8):50-2.

CMS responds to Medicare Hospice Benefit questions.

Neigh JE.

Hospice Association of America, USA. jen@nahc.org

PMID: 15379113 [PubMed - indexed for MEDLINE]

28: Christ Bioeth. 2003 Aug-Dec;9(2-3):343-55.

Intractable symptoms and palliative sedation at the end of life.

Peppin JF.

Iowa Pain Management Clinic, Center for Bioethics Pain Management and Medicine, 1235 8th Street, West Des Moines, Iowa 50265, USA. jpeppin@ipmc.info

PMID: 15255002 [PubMed - indexed for MEDLINE]

29: Clin Cornerstone. 2004;6(1):43-8; discussion 49.

End-of-life care for ethnic minority groups.

Siriwardena AN, Clark DH.

De Montfort University, Division of Primary Care, Leicester, United Kingdom.

Death and dying are profound events that bring into focus important ethical and medical questions for all patients, whatever their cultural background. For ethnic minority groups and their families, specific issues or barriers may arise related to culturally appropriate health care practices, cultural or religious differences, diverse health beliefs, and access to services for care and support during end-of-life conditions. National policy and local initiatives in both the

United States and the United Kingdom support the development of services that address the care of ethnic minorities. This article examines end-of-life care for ethnic minority groups.

PMID: 15255277 [PubMed - indexed for MEDLINE]

30: Clin Geriatr Med. 2004 Aug;20(3):467-75, vi.

Urinary incontinence and the terminally ill older person.

Flaherty JH.

Division of Geriatric Medicine, Saint Louis University School of Medicine, 1402 South Grand Boulevard, Room M238, St. Louis, MO 63104, USA. flaherty@slu.edu

The principles of managing urinary incontinence in an older patient who has a terminal illness should be based on the general principles of overall care for terminally ill older persons. First, health care professionals need to understand "where" the person is in the dying process. Second, they must be able to predict, with as much accuracy as possible, the consequences of any action or inaction (that is, a decision made not to do an intervention that typically is done). Third, they must understand how the patient's symptom is uncomfortable and bothersome from the patient's standpoint. All three steps need to take into account the family's perception of the patient's discomfort, and, whenever possible, the family should be involved in the decision making.

Publication Types:

Review
Review, Tutorial

PMID: 15341808 [PubMed - indexed for MEDLINE]

31: Clin Nurse Spec. 2004 Jul-Aug;18(4):183-5.

The role of neuroleptics in managing morphine-induced terminal delirium: implications for the clinical nurse specialist.

Doorley J, McNeal W.

Wright State University, College of Nursing and Health, 124 University Hall, Dayton, OH 45435, USA. janedoor@msn.com

Publication Types:

Review
Review, Tutorial

PMID: 15273517 [PubMed - indexed for MEDLINE]

32: Crit Care. 2004 Oct;8(5):288-382. Epub 2004 May 21.

Clinical review: Moral assumptions and the process of organ donation in the intensive care unit.

Streat S.

Intensivist, Department of Critical Care Medicine, Auckland Hospital, New Zealand. stephens@adhb.govt.nz.

The objective of the present article is to review moral assumptions underlying organ donation in the intensive care unit. Data sources used include personal experience, and a Medline search and a non-Medline search of relevant English-language literature. The study selection included articles concerning organ donation. All data were extracted and analysed by the author. In terms of data synthesis, a rational, utilitarian moral perspective dominates, and has captured and circumscribed, the language and discourse of organ donation. Examples include "the problem is organ shortage", "moral or social duty or responsibility to donate", "moral responsibility to advocate for donation", "requesting organs" or "asking for organs", "trained requesters", "pro-donation support persons", "persuasion" and defining "maximising donor numbers" as the objective while impugning the moral validity of nonrational family objections to organ donation. Organ donation has recently been described by intensivists in a morally neutral way as an "option" that they should "offer", as "part of good end-of-life care", to families of appropriate patients. In conclusion, the review shows that a rational utilitarian framework does not adequately encompass interpersonal interactions during organ donation. A morally neutral position frees intensivists to ensure that clinical and interpersonal processes in organ donation are performed to exemplary standards, and should more robustly reflect societal acceptability of organ donation (although it may or may not "produce more donors").

PMID: 15469581 [PubMed - in process]

33: Crit Care Med. 2004 Sep;32(9):1839-43.

A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia.

Campbell ML, Guzman JA.

Palliative Care Service, Detroit Receiving Hospital, Detroit, MI, USA.

OBJECTIVES: To compare usual care with a proactive case-finding approach for critically ill patients with terminal dementia using an inpatient palliative care service. **DESIGN:** Prospective comparison to historical control. **SETTING:** Urban, university-affiliated hospital. **PATIENTS:** Total of 52 men and women with end-stage dementia, 26 subjects in each control and intervention group. **INTERVENTIONS:** Proactive case-finding by the palliative care service was done to offer early assistance to the intensive care unit staff about the treatment of patients with terminal dementia. Results were compared with data obtained retrospectively. **MEASUREMENTS AND MAIN RESULTS:** Measurements included age, gender, Acute Physiology and Chronic Health Evaluation Score, Therapeutic Intervention Scoring System, mortality, intensive care unit and hospital lengths of stay, frequency, timing, and goals of do-not-resuscitate orders. The proactive, case-finding approach decreased hospital and medical intensive care

unit length of stay. More important, a proactive palliative intervention decreased the time between identification of the poor prognosis and the establishment of do-not-resuscitate goals, decreased the time terminal demented patients remained in the intensive care unit, and reduced the use of nonbeneficial resources, thus reducing patient burden and the cost of care while having the potential to afford the patient and family increased comfort and psychoemotional support. CONCLUSIONS: Proactive interventions from a palliative care consultant within this subset of patients improved end-of-life care and decreased use of superfluous resources.

PMID: 15343010 [PubMed - indexed for MEDLINE]

34: Crit Care Med. 2004 Aug; 32(8):1789-91.

Comment on:

Crit Care Med. 2004 Aug; 32(8):1648-53.

Nurse-assessed tool for evaluating death in the intensive care unit.

Azoulay E.

Publication Types:

Comment

Editorial

PMID: 15286562 [PubMed - indexed for MEDLINE]

35: Crit Care Med. 2004 Aug; 32(8):1781-4.

Challenges in end-of-life care in the ICU: statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: executive summary.

Thompson BT, Cox PN, Antonelli M, Carlet JM, Cassell J, Hill NS, Hinds CJ, Pimentel JM, Reinhart K, Thijs LG; American Thoracic Society; European Respiratory Society; European Society of Intensive Care Medicine; Society of Critical Care Medicine; Soci  t   de R  animation de Langue Fran  aise.

OBJECTIVE: The purpose of the conference was to provide clinical practice guidance in end-of-life care in the ICU via answers to previously identified questions relating to variability in practice, inadequate predictive models for death, elusive knowledge of patient preferences, poor communication between staff and surrogates, insufficient or absent training of healthcare providers, the use of imprecise and insensitive terminology and incomplete documentation in the medical record. PARTICIPANTS: Presenters and jury were selected by the sponsoring organizations (American Thoracic Society, European Respiratory Society, European Society of Intensive Care Medicine, Society of Critical Care Medicine, Soci  t   de R  animation de Langue Fran  aise). Presenters were experts on the question they addressed. Jury members were general intensivists without special expertise in the areas considered. Experts presented in an open session to jurors and other healthcare professionals. EVIDENCE: Experts prepared review papers on their specific topics in advance of the conference for the

jury's reference in developing the consensus statement. **CONSENSUS PROCESS:** Jurors heard experts' presentations over 2 days and asked questions of the experts during the open sessions. Jury deliberation with access to the review papers occurred for 2 days following the conference. A writing committee drafted the consensus statement for review by the entire jury. The 5 sponsoring organizations reviewed the document and suggested revisions to be incorporated into the final statement. **CONCLUSIONS:** Strong recommendations for research to improve end-of-life care were made. The jury advocates a shared approach to end-of-life decision-making involving the caregiver team and patient surrogates. Respect for patient autonomy and the intention to honor decisions to decline unwanted treatments should be conveyed to the family. The process is one of negotiation, and the outcome will be determined by the personalities and beliefs of the participants. Ultimately, it is the attending physician's responsibility, as leader of the team, to decide on the reasonableness of the planned action. If a conflict cannot be resolved, an ethics consultation may be helpful. The patient must be assured of a pain-free death. The jury subscribes to the moral and legal principles that prohibit administering treatments specifically designed to hasten death. The patient must be given sufficient analgesia to alleviate pain and distress; if such analgesia hastens death, this "double-effect" should not detract from the primary aim to ensure comfort.

Publication Types:

Consensus Development Conference
Review

PMID: 15286559 [PubMed - indexed for MEDLINE]

36: Crit Care Med. 2004 Aug; 32(8):1648-53.

Comment in:

Crit Care Med. 2004 Aug; 32(8):1789-91.

Factors associated with nurse assessment of the quality of dying and death in the intensive care unit.

Hodde NM, Engelberg RA, Treece PD, Steinberg KP, Curtis JR.

Harborview Medical Center, Division of Pulmonary and Critical Care, Department of Medicine, University of Washington, Seattle, WA, USA.

OBJECTIVE: To determine the feasibility of using nurse ratings of quality of dying and death to assess quality of end-of-life care in the intensive care unit and to determine factors associated with nurse assessment of the quality of dying and death for patients dying in the intensive care unit. **DESIGN:** Prospective cohort study. **SETTING:** Hospital intensive care unit. **PATIENTS:** 178 patients who died in an intensive care unit during a 10-month period at one hospital. **INTERVENTIONS:** Nurses completed a 14-item questionnaire measuring the quality of dying and death in the intensive care unit (QODD); standardized chart reviews were also completed. **MEASUREMENTS AND MAIN RESULTS:** Five variables were found to be associated with QODD scores. Higher (better) scores were significantly associated with having someone present at the time of death ($p < .001$), having life support withdrawn ($p = .006$), having an acute diagnosis such as intracranial hemorrhage or trauma ($p = .007$), not having cardiopulmonary

resuscitation in the last 8 hrs of life ($p < .001$), and being cared for by the neurosurgery or neurology services ($p = .002$). Patient age, chronic disease, and Glasgow Coma Scale scores were not associated with the 14-item QODD. Using multivariate analyses, we identified three variables as independent predictors of the QODD score: a) not having cardiopulmonary resuscitation performed in the last 8 hrs of life; b) having someone present at the moment of death; and c) being cared for by neurosurgery or neurology services. CONCLUSIONS: Intensive care unit nurse assessment of quality of dying and death is a feasible method for obtaining quality ratings. Based on nurse assessments, this study provides evidence of some potential targets for interventions to improve the quality of dying for some patients: having someone present at the moment of death and not having cardiopulmonary resuscitation in the last 8 hrs of life. If nurse-assessed quality of dying is to be a useful tool for measuring and improving quality of end-of-life care, it is important to understand the factors associated with nurse ratings.

PMID: 15286539 [PubMed - indexed for MEDLINE]

37: Crit Care Nurse. 2004 Aug;24(4):30-5.

Profiles in dignity: perspectives on nursing and critically ill older adults.

Jacelon CS, Henneman EA.

School of Nursing, University of Massachusetts, Amherst, Mass, USA.

Publication Types:

Case Reports

Review

Review, Tutorial

PMID: 15341232 [PubMed - indexed for MEDLINE]

38: Geriatr Nurs. 2004 Jul-Aug;25(4):233-7.

Gerontological advance practice nurses: as end-of-life care facilitators.

Henderson ML.

School of Nursing, University of North Carolina, Chapel Hill, USA.

Gerontological advance practice nurses (GAPNs) are ideal providers to assist elderly patients with advanced chronic illness and their families as they experience the final phase of life. The goal of this individualized process is for the patient to experience a "good death"-one that is comfortable and self-determined. This article proposes a model in which the GAPN offers 5 essential services in caring for the patient and family based on their needs and on the principles of end-of-life (EOL) care: 1) assessment of the living situation; 2) symptom management and enhancement of quality of life; 3) advance care planning (ACP); 4) patient and family counseling (emotional, social, spiritual); and 5) continuity, communication, and coordination of care.

PMID: 15311200 [PubMed - indexed for MEDLINE]

39: Gerontology. 2004 Jul-Aug;50(4):247-54.

Living will, resuscitation preferences, and attitudes towards life in an aged population.

Laakkonen ML, Pitkala KH, Strandberg TE, Berglind S, Tilvis RS.

Helsinki City Hospital Koskela, Helsinki, Finland. marja-liisa.laakkonen@hel.fi

BACKGROUND: The growth of life-sustaining medical technology and greater attention to medical care at the end of life have provoked interest in issues related to advance care planning. **OBJECTIVE:** To investigate how having a living will (LW), resuscitation preferences, health condition, and life attitudes are related in home-dwelling elderly people. **METHODS:** In a cross-sectional descriptive study, detailed assessments were made of 378 home-dwelling elderly individuals participating in a cardiovascular prevention study (DEBATE Study). The participants were inquired about a preexistence of a written document (LW) concerning life-sustaining care, preferences of cardiopulmonary resuscitation (CPR) in their current situation, and attitudes towards life. General health, physical and cognitive functioning, the presence of depression, and quality of life were also assessed. **RESULTS:** Forty-four of the 378 participants (12%) had a LW. As compared with those without one ($n = 334$), there were more women [82% (36/44) vs. 63% (210/334)] and widows [57% (25/44) vs. 41% (135/334)] among those with a LW. They were also more educated and considered their health to be better. Despite having a LW, 46% (20/44) of them preferred CPR in their current condition, a proportion not statistically different from the 58% (194/334) of the individuals without a LW. In the whole sample, 39% (149/378) of the individuals preferred to forgo CPR. As compared with those preferring CPR, they were older, more often women, and widowed. Participants preferring to forgo CPR had a poorer quality of life, were more lonely, and showed signs of depression more often than those preferring CPR. The preference to forgo CPR was related to attitudes towards life regardless of physical or cognitive functioning. **CONCLUSIONS:** Having a LW does not reduce the reported preference of CPR which is related more to current mental status and life attitudes. In-depth assessment of the patient's preferences should be performed in any comprehensive care plan. Copyright 2004 S. Karger AG, Basel

PMID: 15258431 [PubMed - indexed for MEDLINE]

40: Hastings Cent Rep. 2004 May-Jun;34(3):49.

A tale of two conversations.

Cohen RW.

Wellstar Health Systems, Marietta, Georgia, USA.

PMID: 15281726 [PubMed - indexed for MEDLINE]

41: Health Aff (Millwood). 2004 Jul-Aug;23(4):283; author reply 283-4.

Comment on:

Health Aff (Millwood). 2004 May-Jun;23(3):222-7.

Health Aff (Millwood). 2004 May-Jun;23(3):228-32.

End-of-life stories.

Lynn J.

Publication Types:

Comment

Letter

PMID: 15318590 [PubMed - indexed for MEDLINE]

42: Home Health Care Serv Q. 2004;23(2):41-53.

Physicians as medical center "extenders" in end-of-life care: physician home visits as the lynch pin in creating an end-of-life care system.

Cherin DA, Enguidanos SM, Jamison P.

California State University, 9001 Stockdale Highway, Bakersfield, CA 93311, USA.

The article reviews a successful community-based end-of-life home care program. Specifically, physician visits were compared in the models of care studied, and it was concluded that the community-based model patients benefited significantly over the standard model of care patients due to the use of physicians.

PMID: 15256350 [PubMed - indexed for MEDLINE]

43: Int Nurs Rev. 2004 Sep;51(3):149-58.

Nursing the dying: essential elements in the care of terminally ill patients.

de Araujo MM, da Silva MJ, Francisco MC.

Nurse School, Universidade de Sao Paulo, Brazil.

AIM: To verify those aspects of care that nurses view as important when assisting patients beyond therapeutic possibilities and who are not under intensive care. OBJECTIVES: (1) To find out how nurses cope with daily confrontation with the death and suffering of dying patients, (2) To identify whether nurses feel it is important to have communication skills in order to assist the terminally ill patient, (3) To estimate nurses' degree of work satisfaction, and (4) To explore the humane aspects of nursing assistance to the dying. METHOD: Data were collected in January and February of 2002 by means of individual semistructured interviews with 14 nurses from the unit of haematology at a general hospital in the city of Sao Paulo, Brazil. Interviews were

recorded, transcribed, and further analysed according to the qualitative method proposed by Bardin (1977). RESULTS: We found that Brazilian nurses caring for dying patients should be receiving psychological and emotional support. Results also highlighted different individual approaches in the endeavour to communicate with terminally ill patients, as well as the avoidance patterns developed by some nurses. The latter appeared to be as a result of personal difficulties in coping with the reality of human suffering and death. Finally, there is a need for better preparation in communication skills for nurses caring for terminally ill patients. CONCLUSION: Although the number of interviewed nurses in our study was small, the results corroborated the findings of other studies on the subject.

PMID: 15285741 [PubMed - indexed for MEDLINE]

44: Intensive Care Med. 2004 May; 30(5):770-84. Epub 2004 Apr 20.

Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003.

Carlet J, Thijs LG, Antonelli M, Cassell J, Cox P, Hill N, Hinds C, Pimentel JM, Reinhart K, Thompson BT.

Reanimation Polyvalente, Fondation Hopital St Joseph, 185 rue Raymond Losserand, 75674 Paris CEDEX 14, France. jcarlet@hopital-saint-joseph.org

The jurors identified numerous problems with end of life in the ICU including variability in practice, inadequate predictive models for death, elusive knowledge of patient preferences, poor communication between staff and surrogates, insufficient or absent training of health-care providers, the use of imprecise and insensitive terminology, and incomplete documentation in the medical records. The jury strongly recommends that research be conducted to improve end-of-life care. The jury advocates a "shared" approach to end-of-life decision-making involving the caregiver team and patient surrogates. Respect for patient autonomy and the intention to honour decisions to decline unwanted treatments should be conveyed to the family. The process is one of negotiation, and the outcome will be determined by the personalities and beliefs of the participants. Ultimately, it is the attending physician's responsibility, as leader of the health-care team, to decide on the reasonableness of the planned action. In the event of conflict, the ICU team may agree to continue support for a predetermined time. Most conflicts can be resolved. If the conflict persists, however, an ethics consultation may be helpful. Nurses must be involved in the process. The patient must be assured of a pain-free death. The jury of the Consensus Conference subscribes to the moral and legal principles that prohibit administering treatments specifically designed to hasten death. The patient must be given sufficient analgesia to alleviate pain and distress; if such analgesia hastens death, this "double effect" should not detract from the primary aim to ensure comfort.

Publication Types:

Consensus Development Conference
Review

PMID: 15098087 [PubMed - indexed for MEDLINE]

45: J Am Geriatr Soc. 2004 Sep;52(9):1574-5.

Comment on:

J Am Geriatr Soc. 2004 Sep;52(9):1424-9.

Oregon's lessons for improving advance care planning.

Lorenz KA, Lynn J.

Publication Types:

Comment

Editorial

PMID: 15341565 [PubMed - indexed for MEDLINE]

46: J Am Geriatr Soc. 2004 Sep;52(9):1430-4.

The Physician Orders for Life-Sustaining Treatment program: Oregon emergency medical technicians' practical experiences and attitudes.

Schmidt TA, Hickman SE, Tolle SW, Brooks HS.

Center for Ethics in Health Care, Oregon Health and Science University,
Portland, Oregon 97239, USA. schmidt@ohsu.edu

OBJECTIVES: To evaluate emergency medical technicians' (EMTs) experiences with the Physician Orders for Life-Sustaining Treatment (POLST) program and learn about attitudes regarding its effectiveness. **DESIGN:** Anonymous survey mailed to a stratified random sample. **SETTING:** Tri-County Portland, Oregon, area. **PARTICIPANTS:** A total of 572 Oregon EMT respondents (out of 1,048 surveys) were included in the analysis. **MEASUREMENTS:** Survey questions about experiences with the POLST form and opinions about POLST. **RESULTS:** Respondents were mostly male (76%) and paramedics (66%). Most respondents (73%) had treated a patient with a POLST, and 74% reported receiving education about POLST. EMTs reported that POLST, when present, changed treatment in 45% of cases. Seventy-five percent of the respondents agreed that the POLST form provides clear instructions about patient preferences, and 93% agreed that the POLST form is useful in determining which treatments to provide when the patient is in cardiopulmonary arrest. Fewer (63%) agreed that the form is useful in determining treatments when the patient has a pulse and is breathing. **CONCLUSION:** Most respondents have experience with the POLST program. EMTs find the POLST form useful and often use it to change treatment decisions for patients. Copyright 2004 American Geriatrics Society

PMID: 15341542 [PubMed - indexed for MEDLINE]

47: J Am Geriatr Soc. 2004 Sep;52(9):1424-9.

Comment in:

J Am Geriatr Soc. 2004 Sep;52(9):1574-5.

Use of the Physician Orders for Life-Sustaining Treatment program in Oregon nursing facilities: beyond resuscitation status.

Hickman SE, Tolle SW, Brummel-Smith K, Carley MM.

School of Nursing, Oregon Health & Science University, Portland, Oregon 97239, USA. hickmans@ohsu.edu

OBJECTIVES: Program was designed to communicate resident/surrogate treatment preferences in the form of medical orders. To assess statewide nursing facility use of the Physician Orders for Life-Sustaining Treatment (POLST) and to identify the patterns of orders documented on residents' POLST forms. **DESIGN:** Telephone survey; on-site POLST form review. **SETTING:** Oregon nursing facilities. **PARTICIPANTS:** One hundred forty-six nursing facilities in the telephone survey; 356 nursing facility residents aged 65 and older at seven nursing facilities in the POLST form review. **MEASUREMENTS:** A telephone survey; onsite POLST form reviews. **RESULTS:** In the telephone survey, 71% of facilities reported using the POLST program for at least half of their residents. In the POLST form review, do-not-resuscitate (DNR) orders were present on 88% of POLST forms. On forms indicating DNR, 77% reflected preferences for more than the lowest level of treatment in at least one other category. On POLST forms indicating orders to resuscitate, 47% reflected preferences for less than the highest level of treatment in at least one other category. The oldest old ($>$ or $=$ 85, $n=167$) were more likely than the young old (65-74, $n=48$) to have orders to limit resuscitation, medical treatment, and artificial nutrition and hydration. **CONCLUSION:** The POLST program is widely used in Oregon nursing facilities. A majority of individuals with DNR orders requested some other form of life-extending treatment, and advanced age was associated with orders to limit treatments. Copyright 2004 American Geriatrics Society

PMID: 15341541 [PubMed - indexed for MEDLINE]

48: J Am Geriatr Soc. 2004 Aug;52(8):1331-6.

Hospice care in nursing homes: is site of care associated with visit volume?

Miller SC.

Center for Gerontology and Health Care Research and Department of Community Health, Brown University School of Medicine, Providence, Rhode Island 02912, USA. Susan_Miller@brown.edu

OBJECTIVES: To determine factors associated with hospice visit volume and to examine whether visit volume differs by nursing home (NH) versus non-NH setting. **DESIGN:** Retrospective cohort study. **SETTING:** Twenty-one hospices across seven states under the ownership of one parent provider. **PARTICIPANTS:** Hospice patients from October 1998 through September 1999 in NH ($n=9,460$) and non-NH ($n=15,484$) settings. **MEASUREMENTS:** Data were from the provider's centralized information system. Average daily visit volume was the number of visits divided by the number of hospice routine home care days (days not in hospice inpatient or continuous home care). Multivariate logistic regression tested the association between site of care and an individual's probability of having average daily visits above the sample median. **RESULTS:** Average daily

visits+/-standard deviation were 1.1+/-1.1 for NH and 1.2+/-1.3 for non-NH hospice patients. Site of care was not significantly associated with having an average daily visit volume above the sample median, but patients in NH settings had a lower probability of having a nurse average daily visit volume above the median (adjusted odds ratio (AOR)=0.59, 95% confidence interval (CI)=0.46-0.74) and a greater probability of having social worker (AOR=2.46, 95% CI=1.87-3.24), aide (AOR=1.97; 95% CI=1.11-3.48), and clergy (AOR=3.23, 95% CI=2.21-4.44) average daily visits above the median than those in non-NH settings. CONCLUSION: A different mix, not volume, of services appears to be used to address the physical, psychosocial, and spiritual needs of hospice patients/families who reside in NH settings than of those in non-NH settings.

PMID: 15271122 [PubMed - indexed for MEDLINE]

49: J Am Geriatr Soc. 2004 Aug;52(8):1284-92.

Government expenditures at the end of life for short- and long-stay nursing home residents: differences by hospice enrollment status.

Miller SC, Intrator O, Gozalo P, Roy J, Barber J, Mor V.

Center for Gerontology and Health Care Research, Brown University School of Medicine, Providence, Rhode Island 02919, USA. Susan_Miller@brown.edu

OBJECTIVES: To examine end-of-life government expenditures for short- and long-stay Medicare- and Medicaid-eligible (dual-eligible) nursing home (NH) hospice and nonhospice residents. DESIGN: A retrospective cohort study. SETTING: Six hundred fifty-seven Florida NHs. PARTICIPANTS: Dual-eligible NH residents who died in Florida NHs between July and December 1999 (N=5,774).

MEASUREMENTS:

Nursing home stays of 90 days or less were considered short stays (n=1,739), and those over 90 days were long stays (n=4,035). Three diagnosis groups were studied: cancer without Alzheimer's disease or dementia, Alzheimer's disease or dementia, and other diagnoses. Eligibility and expenditure claims data for 1998 and 1999 were merged with vital statistics and NH resident assessment data to determine diagnoses, location of death, hospice enrollment, eligibility, and expenditures. RESULTS: Twenty percent of short-stay (n=350) and 26% of long-stay (n=958) NH decedents elected hospice; of these, 73% of short-stay and 58% of long-stay NH residents had hospice stays of 30 days or less. Overall, mean government expenditures in the last month of life were significantly less for hospice than nonhospice residents (7,365 dollars; 95% confidence interval (CI)=7,144-7586 dollars vs 8,134 dollars; 95% CI=7,896-8,372 dollars), but 1-month expenditures were only significantly lower for hospice residents with short NH stays, not for those with long NH stays. CONCLUSION: Overall, hospice care in NHs does not appear to increase government expenditures. Because significantly lower expenditures are observed for short-stay NH hospice residents, policy restricting access to Medicare hospice for Medicare skilled nursing facility residents may represent a missed opportunity for savings.

PMID: 15271115 [PubMed - indexed for MEDLINE]

50: J Gen Intern Med. 2004 May;19(5 Pt 2):540-4.

A workshop to teach medical students communication skills and clinical knowledge about end-of-life care.

Torke AM, Quest TE, Kinlaw K, Eley JW, Branch WT Jr.

Department of Medicine, Emory University, Atlanta, GA 30303, USA.
atorke@emory.edu

We describe a half-day workshop to teach third-year medical students three focused end-of-life care skills: breaking bad news, discussing advance directives, and assessing and managing pain. Our workshop included a readers' theater exercise and three role-play exercises. In two of the workshops, faculty members played the role of patients. We used readers' theater to engage the students on an emotional level and set a reflective tone for the workshop. Evaluations reflected that most respondents felt that the workshop enhanced their understanding and ability to address these skills with patients. By 6 months, many students reported applying these skills to patient care in a way they thought was effective.

PMID: 15109320 [PubMed - indexed for MEDLINE]

51: J Gerontol Nurs. 2004 Sep;30(9):37-46.

Physician orders for life-sustaining treatment form: honoring end-of-life directives for nursing home residents.

Meyers JL, Moore C, McGrory A, Sparr J, Ahern M.

Intercollegiate College of Nursing, Washington State University College of Nursing, Spokane, Washington 99224-5428, USA.

Physician Orders for Life-Sustaining Treatment (POLST) form provides choices about end-of-life care and gives these choices the power of physician orders. The POLST form assures end-of-life choices can be implemented in all settings, from the home through the health-care continuum. The use of the POLST form was evaluated in a pilot study in nursing homes in two eastern Washington counties. Chart reviews and template analysis of interviews revealed the POLST form accurately conveyed end-of-life wishes in 19 of 21 cases. An informed consent process was evidenced in 16 of 21 cases, and the POLST form was congruent with residents' existing advance directives for health care. The findings support the continued use, development, and evaluation of this promising tool for improving end-of-life care.

PMID: 15471062 [PubMed - in process]

52: J Med Ethics. 2004 Oct;30(5):499-503.

Internists' attitudes towards terminal sedation in end of life care.

Kaldjian LC, Jekel JF, Bernene JL, Rosenthal GE, Vaughan-Sarrazin M, Duffy TP.

Department of Internal Medicine, University of Iowa Carver College of Medicine,
200 Hawkins Drive, Iowa City, IA 52242, USA. lauris-kaldjian@uiowa.edu.

OBJECTIVE: To describe the frequency of support for terminal sedation among internists, determine whether support for terminal sedation is accompanied by support for physician assisted suicide (PAS), and explore characteristics of internists who support terminal sedation but not assisted suicide. DESIGN: A statewide, anonymous postal survey. SETTING: Connecticut, USA. PARTICIPANTS: 677

Connecticut members of the American College of Physicians. Measurements: Attitudes toward terminal sedation and assisted suicide; experience providing primary care to terminally ill patients; demographic and religious characteristics. RESULTS: 78% of respondents believed that if a terminally ill patient has intractable pain despite aggressive analgesia, it is ethically appropriate to provide terminal sedation (diminish consciousness to halt the experience of pain). Of those who favoured terminal sedation, 38% also agreed that PAS is ethically appropriate in some circumstances. Along a three point spectrum of aggressiveness in end of life care, the plurality of respondents (47%) were in the middle, agreeing with terminal sedation but not with PAS. Compared with respondents who were less aggressive or more aggressive, physicians in this middle group were more likely to report having more experience providing primary care to terminally ill patients ($p = 0.02$) and attending religious services more frequently ($p < 0.001$). CONCLUSIONS: Support for terminal sedation was widespread in this population of physicians, and most who agreed with terminal sedation did not support PAS. Most internists who support aggressive palliation appear likely to draw an ethical line between terminal sedation and assisted suicide.

PMID: 15467087 [PubMed - in process]

53: J Med Ethics. 2004 Jun; 30(3):275-8.

Medical futility and physician discretion.

Wreen M.

Department of philosophy, Marquette University, Milwaukee, WI 53201-1881, USA.
Michael.Wreen@Marquette.edu

Some patients have no chance of surviving if not treated, but very little chance if treated. A number of medical ethicists and physicians have argued that treatment in such cases is medically futile and a matter of physician discretion. This paper critically examines that position. According to Howard Brody and others, a judgment of medical futility is a purely technical matter, which physicians are uniquely qualified to make. Although Brody later retracted these claims, he held to the view that physicians need not consult the patient or his family to determine their values before deciding not to treat. This is because professional integrity dictates that treatment should not be undertaken. The argument for this claim is that medicine is a profession and a social practice, and thus capable of breaches of professional integrity. Underlying professional integrity are two moral principles, one concerning harm, the other fraud. According to Brody both point to the fact that when the odds of survival are very low treatment is a violation of professional integrity. The details of this skeletal argument are exposed and explained, and the full argument is

criticised. On a number of counts, it is found wanting. If anything, professional integrity points to the opposite conclusion.

PMID: 15173362 [PubMed - indexed for MEDLINE]

54: J Obstet Gynaecol Can. 2004 Jul;26(7):621, 623.

Compassion in life, caring in death: a view from the other side.

[Article in English, French]

Chamberlain J.

Publication Types:
Editorial

PMID: 15248930 [PubMed - indexed for MEDLINE]

55: J Pain Symptom Manage. 2004 Oct;28(4):306-315.

Agreement among family members in their assessment of the Quality of Dying and Death.

Mularski R, Curtis JR, Osborne M, Engelberg RA, Ganzini L.

Department of Medicine (R.M., M.O.), Division of Pulmonary and Critical Care Medicine VA Greater Los Angeles Healthcare System, and Department of Health Services (R.M.), The University of California, Los Angeles School of Public Health, Los Angeles, California; Departments of Medicine (J.R.C., R.A.E.) and Health Services (J.R.C.), University of Washington and Harborview Medical Center, Seattle, Washington; Department of Psychiatry, Mental Health Division (L.G.), Oregon Health & Science University and Portland Veterans Affairs Medical Center, Portland Oregon, USA.

Improving end-of-life care requires accurate indicators of the quality of dying. The purpose of this study was to measure the agreement among family members who rate a loved one's dying experience. We administered the Quality of Dying and Death instrument to 94 family members of 38 patients who died in the intensive care unit. We measured a quality of dying score of 60 out of 100 points and found moderate agreement among family members as measured by an intraclass correlation coefficient (ICC) of 0.44. Variability on individual items ranged from an ICC of 0.15 to 1.0. Families demonstrated more agreement on frequencies of events (ICC 0.54) than on determinations of quality (ICC 0.32). These findings reveal important variability among family raters and suggest that until the variability is understood, multiple raters may generate more comprehensive end-of-life data and may more accurately reflect the quality of dying and death.

PMID: 15471648 [PubMed - as supplied by publisher]

56: J Palliat Med. 2004 Jun; 7(3):486-93.

The Balm of Gilead Project: a demonstration project on end-of-life care for safety-net populations.

Kvale EA, Williams BR, Bolden JL, Padgett CG, Bailey FA.

Center for Palliative Care, Division of Gerontology and Geriatric Medicine, University of Alabama at Birmingham, Birmingham, Alabama 35294, USA.

The Balm of Gilead is a comprehensive program of end-of-life care for the populations served by the "safety net" public health system in Alabama's largest county. The Balm of Gilead serves terminally ill persons, predominantly of minority ethnic status who as a group are relatively younger than the national hospice population, and typically lacking in personal financial resources. Care provided by the Balm of Gilead addresses the holistic needs associated with terminal illness in each of its stages and each of its treatment settings. Balm of Gilead professionals and volunteers provide continuity of care across a continuum that includes inpatient palliative care, home hospice services, and specialized palliative care in nursing homes and other community residential settings. Cooper Green Hospital and the Jefferson County Department of Health are principal partners in the program. Community partnerships with local foundations, colleges and universities, faith communities, civic groups, and professional groups complete the collaborative network of the Balm of Gilead Project. This report discusses work to date toward fulfilling the project's two primary objectives: (1) to build the infrastructure necessary to support a comprehensive palliative care program that is available to county residents regardless of their ability to pay and (2) to develop systems and services to foster the institutional and community values that promote excellence in end-of-life care. The Project's current status and future challenges are reviewed.

PMID: 15265364 [PubMed - indexed for MEDLINE]

57: J Palliat Med. 2004 Jun; 7(3):477-80.

Communication across cultures.

Hallenbeck JL.

Stanford University School of Medicine, Director, Palliative Care Services, VA Palo Alto HCS, Palo Alto, California 94304, USA. james.hallenbeck@med.va.gov

Publication Types:
Case Reports

PMID: 15265361 [PubMed - indexed for MEDLINE]

58: J Palliat Med. 2004 Jun; 7(3):473-4.

Responding to patient emotion #29.

Ambuel B.

Department of Family and Community Medicine, Medical College of Wisconsin,
Milwaukee, Wisconsin, USA. bruce.ambuel@phci.org

PMID: 15265359 [PubMed - indexed for MEDLINE]

59: J Palliat Med. 2004 Jun; 7(3):472-3.

Broaching the topic of a palliative care consultation with patients and families
#42.

Arnold RM, Weissman DE.

University of Pittsburgh Medical Center, Department of Medicine, Pittsburgh,
Pennsylvania, USA. rabob@pitt.edu

PMID: 15265358 [PubMed - indexed for MEDLINE]

60: J Palliat Med. 2004 Jun; 7(3):469-71.

Comment on:

J Palliat Med. 2004 Jun; 7(3): 451-61.

Opening the black box: physicians' inner responses to patients' requests for
physician-assisted death.

Quill TE.

Publication Types:

Comment
Editorial

PMID: 15265357 [PubMed - indexed for MEDLINE]

61: J Palliat Med. 2004 Jun; 7(3):451-61.

Comment in:

J Palliat Med. 2004 Jun; 7(3): 469-71.

Oregon physicians' responses to requests for assisted suicide: a qualitative
study.

Dobscha SK, Heintz RT, Press N, Ganzini L.

Department of Veterans Affairs, Portland, Oregon 97207, USA.
steven.dobscha@med.va.gov

In 1997, the Oregon Death with Dignity Act was enacted, allowing physicians to
prescribe lethal dosages of medication to competent, terminally ill patients who

request them. To improve our understanding of physicians' reactions to requests for assisted suicide, we performed semistructured interviews of 35 Oregon physicians who had received requests from patients. Interviews were completed in 2000, and audiotaped, transcribed, and analyzed using qualitative techniques. Requests for assisted suicide had a powerful impact on physicians and their practices. Physicians often felt unprepared, and experienced apprehension and discomfort before and after receiving requests. Prominent sources of discomfort included concerns about adequately managing symptoms and suffering, not wanting to abandon patients, and incomplete understanding of patients' preferences, especially when physicians did not know patients well. Participation in assisted suicide required a large investment of time and was emotionally intense. Regardless of whether they prescribed or not, physicians did not express major regrets about their decisions. Requests often facilitated discussion of important issues, and many physicians felt that the process increased their confidence and assertiveness in discussing end-of-life issues with other patients. Physicians rarely sought support from colleagues; instead, they tended to discuss emotional aspects of their experiences with their spouses.

PMID: 15265355 [PubMed - indexed for MEDLINE]

62: J Palliat Med. 2004 Jun;7(3):411-8.

Barriers to hospice care and referrals: survey of physicians' knowledge, attitudes, and perceptions in a health maintenance organization.

Brickner L, Scannell K, Marquet S, Ackerson L.

Department of Internal Medicine, Kaiser Permanente Medical Centers, Oakland, California 94611, USA. leslea.brickner@kp.org

INTRODUCTION: Many proponents of hospice care believe that this service is underutilized. **OBJECTIVE:** To determine physicians' perceptions of hospice utilization and of their own hospice referral pattern; their perceived and actual knowledge of appropriate hospice referral diagnoses; and perceived barriers to hospice referral. **METHODS:** Surveys for anonymous response were distributed to 125 physicians in 2 internal medicine departments of a large not-for-profit health maintenance organization (HMO). Of these 125 physicians, 89% responded, including 91 staff physicians and 20 residents. **RESULTS:** Of the 111 physician-respondents, 78% reported their belief that hospice care was underutilized; 84% were unable to identify appropriate hospice diagnoses; and 12% were aware of the "National Hospice Organization Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases." Difficulty of predicting death to within 6 months was cited by 37% as the foremost barrier to hospice referral. In addition, 28% expressed concern that patients or families would interpret hospice referral as a cost saving measure; 11% of respondents had been accused of using hospice referral for this purpose. **CONCLUSION:** Our study-the first major survey of physician attitudes and practices regarding hospice utilization in an HMO setting-showed that barriers to hospice referral are similar to those in non-HMO settings; physicians have difficulty predicting life expectancy and lack knowledge of patient eligibility guidelines. Physician concern that patients or their family members would construe hospice referral as a cost-saving technique may be a barrier particularly troublesome in an HMO setting.

PMID: 15265350 [PubMed - indexed for MEDLINE]

63: J Palliat Med. 2004 Jun; 7(3):405-7.

Challenges in palliative care research: one experience.

Buss MK, Arnold RM.

Division of Pain and Palliative Care, Dana Farber Cancer Institute, Boston, Massachusetts 02115, USA. Mary_Buss@dfci.harvard.edu

PMID: 15265348 [PubMed - indexed for MEDLINE]

64: J Psychosoc Nurs Ment Health Serv. 2004 Aug; 42(8):34-44.

Dying patients' thoughts of ending their lives: a pilot study of rural New Mexico.

Birkholz G, Gibson JM, Clements PT.

College of Nursing, University of New Mexico, Albuquerque 87131-0001, USA. Gbirkholz@salud.unm.edu

Forty-nine hospice patients in rural New Mexico were directly interviewed concerning their thoughts about ending their lives. Thirty-one patients (63%) did not have thoughts of ending their lives, whereas 18 patients (37%) reported having suicidal thoughts. There were no differences between patients with and without thoughts of suicide related to gender; ethnicity; age; education; disease; religion; importance of religion; location of hospice agency; remaining financial, family, or spiritual issues; satisfaction with hospice care; sum of hospice personnel seen; or sum of medical equipment used. There were significant differences between patients with and without thoughts of suicide related to the number of household members ($p = .02$); the symptoms of trouble sleeping ($p = .04$) and nervousness ($p = .03$); and Medicare insurance coverage for hospice care ($p = .01$). No other symptom, including pain and hopelessness, was significant. Seven (39%) of the 18 patients who thought of ending their lives told someone about these thoughts. There were no variable differences between patients who did and did not tell someone about these thoughts.

PMID: 15354597 [PubMed - indexed for MEDLINE]

65: J R Soc Med. 2004 Sep; 97(9):428-31.

Comment in:

J R Soc Med. 2004 Sep; 97(9):413-4.

Community hospitals: an under-recognized resource for palliative care.

Payne S, Kerr C, Hawker S, Seamark D, Davis C, Roberts H, Jarrett N, Roderick P, Smith H.

Palliative and End-of-Life Care Research Group, University of Sheffield,
Bartolome House, Winter Street, Sheffield, UK. s.a.payne@sheffield.ac.uk

In the UK there are concerns that, in certain groups of dying patients such as the old, those with non-cancer diagnoses and those in rural areas, the quality of care is unacceptably variable. There has been no systematic survey of the extent to which community hospitals provide general palliative care for such patients. Therefore, by means of a structured questionnaire we asked senior nurses/managers at all 478 community hospitals in the UK for information on staff expertise, facilities and specialist equipment, liaison arrangements with specialist palliative care providers, priorities, practice and policy in end-of-life care. Of the 346 hospitals (72%) that responded, only 28 were in urban areas. 73% of hospitals employed at least one nurse with additional training in palliative care, 72% had access to 24-hour specialist palliative care advice and 51% had separate overnight accommodation for relatives, but only 22% had designated palliative care beds. Most hospitals did not have written policies or guidelines for patient assessment or symptom control. These findings add to evidence that community hospitals represent an important resource to improve access to palliative care for groups that are currently under-served.

PMID: 15340022 [PubMed - indexed for MEDLINE]

66: J R Soc Med. 2004 Sep;97(9):413-4.

Comment on:

J R Soc Med. 2004 Sep;97(9):428-31.

Home or hospital? Choices at the end of life.

Gomes B, Higginson IJ.

Publication Types:

Comment
Editorial

PMID: 15340018 [PubMed - indexed for MEDLINE]

67: J Support Oncol. 2004 May-Jun;2(3):283-8.

Withdrawal of ventilatory support from the dying adult patient.

Marr L, Weissman DE.

Medical College of Wisconsin, Palliative Care Center, Division of Neoplastic
Diseases and Related Disorders, Milwaukee, WI 53226, USA. lmarr@mail.mcw.edu

Publication Types:

Case Reports

PMID: 15328827 [PubMed - indexed for MEDLINE]

68: J Support Oncol. 2003 May-Jun;1(1):69-72.

Results from the Last Acts campaign: how can we improve?

Karani R, Meier DE.

Brookdale Department of Geriatrics and Adult Development, Mount Sinai Medical Center, New York, NY 10029, USA. reena.karani@mssm.edu

PMID: 15352649 [PubMed - indexed for MEDLINE]

69: J Support Oncol. 2003 May-Jun;1(1):23-32; discussion 32-4.

Management of dyspnea.

Thomas JR, von Gunten CF.

Center for Palliative Studies, San Diego Hospice, a teaching affiliate of the University of California, San Diego School of Medicine, USA.
jthomas@sdhospice.org

Patients with cancer frequently report dyspnea, the uncomfortable awareness of breathing. Lung involvement with cancer does not predict its occurrence. Patients describe it as one of the most frightening and distressing symptoms, and patient self-report is the only reliable measure. Measurements of respiratory rate, oxygen saturation, and arterial blood gases do not measure dyspnea. Opioids in modest doses have been demonstrated to give effective relief of dyspnea, whether or not identifiable reversible causes exist. Medical management of dyspnea can be directed at the underlying cause when the potential benefits outweigh the burdens of such treatment. In rare cases where symptomatic treatment is unable to control dyspnea to the patient's satisfaction, sedation is an effective, ethical option.

Publication Types:

Review

Review, Tutorial

PMID: 15352640 [PubMed - indexed for MEDLINE]

70: J Telemed Telecare. 2004;10(3):170-4.

An assessment of the readiness of hospice organizations to accept technological innovation.

Oliver DR, Demiris G.

School of Social Work, University of Missouri, Columbia, Missouri 65211, USA.
Oliverdr@missouri.edu

We surveyed seven of the 62 certified hospice programmes in the state of

Missouri. The survey consisted of 19 questions that covered demographic information, how employees received new information, the current use of various forms of technology, employees' comfort with technology and their perceptions of the use of video-phones. A total of 124 surveys were returned. Respondents were categorized within the following disciplines: nurses (48%), administrators and nurse supervisors (6%), social workers (9%), physicians (3%), home health aids (18%), chaplains (5%) and other staff (e.g. clerical and bereavement staff) (12%). Staff reported using several types of technological device at work but not a video-phone or a Web camera. There were significant differences between hospices in the degree of use of computers at work, the number of devices used at work and the perceived benefits of video-phone technology. There were significant differences between disciplines in the degree of use of computers at work and at home, the number of devices used at work, and their comfort both with the use of new technology and with the idea of introducing new technology to patients and their families. Because there were variations in the perceived usefulness of video-phones for hospice care, the introduction of such equipment would require substantial involvement of the users.

Publication Types:
Multicenter Study

PMID: 15165444 [PubMed - indexed for MEDLINE]

71: Med Care. 2004 Sep;42(9):871-4.

Accommodating ethnic diversity: a study of California hospice programs.

Lorenz KA, Ettner SL, Rosenfeld KE, Carlisle D, Liu H, Asch SM.

VA Greater Los Angeles Healthcare System, Los Angeles, California 90073, USA.
karl.lorenz@med.va.gov

BACKGROUND: Studies have confirmed ethnic disparities in the use of hospice services and identified barriers that minorities face in accessing care. **OBJECTIVES:** We sought to determine whether hospices provide services that might affect minority participation. **RESEARCH DESIGN:** We surveyed California hospices to determine whether programs use diverse health care providers and volunteers, offer translation, diverse spiritual care, or outreach materials and whether they plan to expand such services. Linking the data to the California Office of Statewide Health Planning and Development annual home care and hospice survey and 2000 US Census, we used multivariate linear regression to evaluate the relationship of program characteristics (profit status, size, chain/freestanding status, urban/rural location, and proportion of nonwhite residents) to services that might affect minority participation. **SUBJECTS:** One hundred of 149 programs that we surveyed responded. **RESULTS:** Many programs offer translation (81%), diverse providers (63%) and volunteers (64%), and culturally diverse spiritual services (52%). Few (21%) were conducting outreach, but 23/25 programs expanding services reported plans to improve outreach. In multivariate models adjusted for program size, chain status, profit status, urban/rural location, proportion of nonwhite residents, we found that larger hospices and those in ethnically diverse zip codes were more likely to offer such services. Larger hospices are more likely to report expanding such services. **CONCLUSIONS:** Many hospices are making efforts to accommodate ethnically diverse patients, but a substantial

number are not. Culturally appropriate care and outreach should be addressed in efforts to improve the acceptability and experience of hospice care among minorities.

PMID: 15319612 [PubMed - indexed for MEDLINE]

72: Monaldi Arch Chest Dis. 2004 Jan-Mar;61(1):50-7.

Ethics, attitude and practice in end-of-life care decision: an European perspective.

Nava S.

Respiratory Unit, "Salvatore Maugeri" Foundation IRCCS, Scientific Institute of Pavia, Italy. snava@fsm.it

Only in the last decade in Europe has there been increased attention dedicated to the end-of-life care in the hospital, especially in the Intensive Care Unit (ICU). The definitions of the potential decision are extremely important. Withholding is a planned decision not to institute therapies that were otherwise warranted, Withdrawal is the discontinuation of treatments that had been started, Terminal sedation consists of pain and symptom treatment with the possible side effect of shortening life, while Euthanasia means that a doctor is intentionally killing a person who is suffering unbearably and hopelessly at the latter's explicit informed request. The overall incidence of these practices in Europe is only partially known, but there are important differences between Countries or regions, reflecting the absence of a common strategy even within the European Community. Only <15% of ICU patients retain decision making capacity, allowing the impossibility of discussing the decision with them. It is rare that the patient's family is involved in the decision and when such case does arise, the relatives rate the communication with hospital staff poor. The "shared decision" taken together by physicians, nurses, and the patient's family may be the best approach for end-of-life decision, therefore common European guidelines are needed.

PMID: 15366337 [PubMed - in process]

73: Nephrol Nurs J. 2004 May-Jun;31(3):263.

Caring through the end of life.

Dinwiddie LC.

PMID: 15303422 [PubMed - indexed for MEDLINE]

74: Nurs Stand. 2004 Jul 28-Aug 3;18(46):16-7.

A release from suffering. Supporters of a bill being introduced to parliament hope to make assisted dying legal while still protecting the vulnerable.

Duffin C.

PMID: 15338923 [PubMed - indexed for MEDLINE]

75: Nurs Times. 2004 Aug 3-9;100(31):34-5.

The use of pastoral and spiritual support in bereavement care.

Lomas D, Timmins J, Harley B, Mates A.

Pastoral care team, United Lincolnshire Hospitals NHS Trust.

For many people, the death of a loved one can result in feelings of shock, numbness or denial, even though they may have been expecting it for some time. Pastoral and spiritual care is a vital part of an authentic, holistic health care service. Nurses need to be aware of the needs of relatives and friends of the deceased and understand their role in practical matters such as death certificates, cremation forms and last offices.

PMID: 15360079 [PubMed - indexed for MEDLINE]

76: NY Times (Print). 2004 Jul 14:A23.

Choosing death.

Kristof ND.

Publication Types:
Newspaper Article

PMID: 15290805 [PubMed - indexed for MEDLINE]

77: Oncol Nurs Forum. 2004 Sep 17;31(5):954-60. Print 2004 Sep.

Patient Control and End-of-Life Care Part II: The Advanced Practice Nurse Perspective.

Volker DJ, Kahn D, Penticuff J.

Austin School of Nursing, University of Texas, Austin, TX, USA.
dvolker@mail.nur.utexas.edu

PURPOSE/OBJECTIVES: To explore the nature of what people with advanced cancer want regarding personal control and comfort at the end of life. RESEARCH APPROACH: Descriptive, naturalistic, using Denzins model of interpretive interactionism. SETTING: A variety of urban and rural communities throughout the state of Texas. PARTICIPANTS: 7 people with advanced cancer diagnoses. METHODOLOGIC APPROACH: Participants were recruited via oncology advanced practice nurses who also participated in the study. Interviews were recorded on audiotape and analyzed via Denzins interpretive process of data analysis. MAIN

Library Program Office
Office of Information
Veterans Health Administration

RESEARCH VARIABLES: Patient control. FINDINGS: Thematic analysis revealed six themes: protection of dignity, control of pain and other symptoms associated with disease, management of treatment, management of how remaining time is spent, management of impact on family, and control over the dying process. CONCLUSIONS: Participants expressed a wide variety of preferences for personal control and comfort. Their desires reflected personal values and beliefs about how they spend their time and how they want control over their care. INTERPRETATION: Nurses must be sensitive to the variety of preferences their patients with advanced cancer may have for engagement in decisions regarding treatment, care management, and activities of daily life.

PMID: 15378096 [PubMed - in process]

78: Oncol Nurs Forum. 2004 Sep 17;31(5):945-53. Print 2004 Sep.

Patient Control and End-of-Life Care Part I: The Advanced Practice Nurse Perspective.

Volker DJ, Kahn D, Penticuff J.

Austin School of Nursing, University of Texas, Austin, TX, USA.
dvolker@mail.nur.utexas.edu

PURPOSE/OBJECTIVES: To explore understanding of preferences of adult patients with cancer for control in the context of end-of-life care and to explore strategies that oncology advanced practice nurses (APNs) use to assist patients in achieving personal control at the end of life. RESEARCH APPROACH: Descriptive, naturalistic using Denzin's model of interpretive interactionism. SETTING: A variety of settings throughout the state of Texas. PARTICIPANTS: 9 oncology APNs. METHODOLOGIC APPROACH: Participants were recruited via a mailed invitation to APN members of the Oncology Nursing Society who resided in Texas. Interviews were recorded on audiotape and analyzed via Denzin's interpretive process of data analysis. MAIN RESEARCH VARIABLES: Patient control. FINDINGS: APNs' descriptions of patient preferences for control at the end of life included engagement with living, turning the corner, comfort and dignity, and control over the dying process. APN roles included presenting bad news in a context of choices, managing physical care and emotional needs, and facilitating care services and systems. CONCLUSIONS: Patient desire for control manifests in a wide variety of actions and desires to live fully and remain actively involved in personal decision making in the context of an advanced cancer diagnosis. APNs play a pivotal role in determining and facilitating patient preferences for control. INTERPRETATION: Academic programs to prepare oncology APNs must include attention to communication skills, clinical care needs, and care management strategies for the end-of-life continuum of care. APNs may need to increase efforts to dispel patient and family misperceptions about value and timing of palliative care and hospice services.

PMID: 15378095 [PubMed - in process]

79: Pain Med. 2004 Jun;5(2):214-7; discussion 218-28.

The debate on elder abuse for undertreated pain.

Tucker KL.

Compassion in Dying Federation, Affiliate Professor of Law, University of Washington School of Law and Seattle University School of Law, Perkins Coie, Of Counsel, Seattle, Washington 98101-3099, USA. ktucker@perkinscoie.com

Presented is a review of the pain management provided to an elderly male patient dying of mesothelioma in an acute care hospital and, subsequently, in a nursing home. Discussed are the medico-legal aspects of the case, including the patient's survivors' efforts to hold the treating physicians, hospital, and nursing home accountable for inadequate pain management through complaints submitted to the state medical board, the state department of health services, and the Center for Medicaid/Medicare Services, and in state court.

Publication Types:
Case Reports

PMID: 15209980 [PubMed - indexed for MEDLINE]

80: Palliat Med. 2004 Sep;18(6):550-7.

Emotional burden of nurses in palliative sedation therapy.

Morita T, Miyashita M, Kimura R, Adachi I, Shima Y.

Palliative Care Team, Seirei Hospice, Seirei Mikatabara Hospital, Hamamatsu, Shizuoka, Japan. seireihc@jt6.so-net.ne.jp

BACKGROUND: Palliative sedation therapy is often required in terminally ill cancer patients, and may cause emotional burden for nurses. The primary aims of this study were 1) to clarify the levels of nurses' emotional burden related to sedation, and 2) to identify the factors contributing to the burden levels. **METHODS:** A questionnaire survey of 3187 nurses, with a response rate of 82%. **RESULTS:** Eighty-two percent of the nurses (n = 2607) had clinical experience in continuous-deep sedation. Thirty per cent reported that they wanted to leave their current work situation due to sedation-related burden (answering occasionally, often, or always). Also, 12% of the nurses stated that being involved in sedation was a burden, 12% that they felt helpless when patients received sedation, 11% that they would avoid a situation in which they had to perform sedation if possible, and 4% that they felt what they had done was of no value when they performed sedation. The higher nurse-perceived burden was significantly associated with shorter clinical experience, nurse-perceived insufficient time in caring for patients, lack of common understanding of sedation between physicians and nurses, team conference unavailability, frequent experience of conflicting wishes for sedation between patient and family, nurse-perceived inadequate interpersonal skills, belief that it was difficult to diagnose refractory symptoms, belief that sedation would hasten death, belief that sedation was ethically indistinguishable from euthanasia, nurse-perceived inadequate coping with their own grief, and nurses' personal values contradictory to sedation therapy. **CONCLUSIONS:** A significant number of nurses felt serious emotional burden related to sedation. To relieve nurses' emotional burden, we encourage 1) management efforts to reduce work overload, 2) a team

approach to resolving conflicting opinions, especially between physicians and nurses, 3) co-ordination of early patient-family meetings to clarify their preferred end-of-life care, 4) education and training about sedation specifically focused on interpersonal skills, systematic approaches to diagnosing refractory symptoms, minimum life-threatening potency in sedation, and ethical principals differentiating sedation from euthanasia, and 5) exploring nurses' personal values through the patient-centered principle.

PMID: 15453626 [PubMed - in process]

81: Patient Educ Couns. 2004 Jul;54(1):15-20.

Judgments of laypersons and general practitioners on justifiability and legality of providing assistance to die to a terminally ill patient: a view from New Zealand.

Mitchell K, Glynn Owens R.

Department of Psychology, University of Auckland, Tamaki Campus, Private Bag 92019, Auckland, New Zealand. k.mitchell@auckland.ac.nz

As part of a larger study, four decisions related to a vignette scenario of the elective death of a terminally ill patient suffering intractable pain are examined (doctor supplying information and drugs, assisting patient to take the drugs, or administering a lethal injection). Judgments on justifiability and legality of actions were obtained from laypersons and general practitioners (GPs) in Auckland, New Zealand. The results show that over 72% of laypersons and over 30% of GPs judged all four actions justified. Despite illegality a significant number of laypersons and some doctors were unsure of the legal status of actions. The current law in New Zealand prohibiting physician-assisted death may not reflect judgments by the majority of laypersons or 30% of general practitioners on the justifiability of elective death options for a terminally ill patient with intractable pain. Judgments on justifiability may be related to confusion over the legality of actions.

PMID: 15210255 [PubMed - indexed for MEDLINE]

82: Provider. 2004 Jul;30(7):28-9, 31-2, 35-7 passim.

Preserving patient dignity when surrogates step in.

Gold MF.

PMID: 15354549 [PubMed - indexed for MEDLINE]

83: Psychooncology. 2004 Jan 8;13(10):700 [Epub ahead of print]

Defining dignity in terminally ill cancer patients: A factor-analytic approach.

Hack TF, Chochinov HM, Hassard T, Kristjanson LJ, McClement S, Harlos M.

CancerCare Manitoba, Winnipeg, Canada.

The construct of 'dignity' is frequently raised in discussions about quality end of life care for terminal cancer patients, and is invoked by parties on both sides of the euthanasia debate. Lacking in this general debate has been an empirical explication of 'dignity' from the viewpoint of cancer patients themselves. The purpose of the present study was to use factor-analytic and regression methods to analyze dignity data gathered from 213 cancer patients having less than 6 months to live. Patients rated their sense of dignity, and completed measures of symptom distress and psychological well-being. The results showed that although the majority of patients had an intact sense of dignity, there were 99 (46%) patients who reported at least some, or occasional loss of dignity, and 16 (7.5%) patients who indicated that loss of dignity was a significant problem. The exploratory factor analysis yielded six primary factors: (1) Pain; (2) Intimate Dependency; (3) Hopelessness/Depression; (4) Informal Support Network; (5) Formal Support Network; and (6) Quality of Life. Subsequent regression analyses of modifiable factors produced a final two-factor (Hopelessness/Depression and Intimate Dependency) model of statistical significance. These results provide empirical support for the dignity model, and suggest that the provision of end of life care should include methods for treating depression, fostering hope, and facilitating functional independence. Copyright 2004 John Wiley & Sons, Ltd.

PMID: 15386643 [PubMed - as supplied by publisher]

84: Resuscitation. 2004 Jun;61(3):333-9.

Advance orders to limit therapy in 67 long-term care facilities in Finland.

Laakkonen ML, Finne-Soveri UH, Noro A, Tilvis RS, Pitkala KH.

Helsinki City Hospital Koskela, P.O. Box 6410, FIN-00099 Helsinki, Finland.
marja-liisa.laakkonen@hel.fi

OBJECTIVE: To assess the documentation of a do-not-attempt-resuscitation (DNAR) or do-not-hospitalize (DNH) orders in the medical record and to determine factors related to these orders. **MATERIALS AND METHODS:** Five thousand six hundred and fifty four subjects from three different levels of institutional long-term care (LTC), chronic care hospitals ($n = 1989$), nursing homes ($n = 3310$), and assisted living ($n = 335$) in 67 LTC facilities in 19 municipalities were assessed. **RESULTS:** Out of these patients, 751 (13%) had a DNAR order and only 36 (0.6%) had a DNH order. The variation in DNAR orders between individual LTC institutions was enormous, ranging from 0 to 92%. In logistic regression analysis, individual institutions and their local caring cultures had the strongest explanatory value ($R(2) = 0.49$) for advance orders to limit therapy. Impaired activity in daily living (ADL) function ($R(2) = 0.11$), impaired cognition ($R(2) = 0.07$), level of LTC ($R(2) = 0.05$), and diagnoses ($R(2) = 0.04$) did not provide adequate explanations. Terminal prognosis was not significantly associated with advance orders. **CONCLUSIONS:** We found marked differences in the use of DNAR and DNH orders between caring units. Diseases and ADL status were only weakly significant as background factors. Open discussions, general guidelines, and research about the adequacy of DNAR decisions are needed to improve equality and self-empowerment among the elderly residing in

institutions.

PMID: 15172713 [PubMed - indexed for MEDLINE]

85: Soc Sci Med. 2004 Dec;59(12):2467-77.

Preferences in end-of-life care of older persons: after-death interviews with proxy respondents.

Klinkenberg M, Willems DL, Onwuteaka-Philipsen BD, Deeg DJ, van der Wal G.

Department of Social Medicine, Institute for Research in Extramural Medicine, VU University Medical Centre, Van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands.

This population-based study employing after-death interviews with proxies describes older persons' preferences regarding medical care at the end of life. Interviews were held with 270 proxy respondents of 342 deceased persons (age range 59-91) in the Netherlands. The deceased were respondents to the Longitudinal Aging Study Amsterdam. The prevalence of advance directives (ADs), preferences for medical decisions at the end of life (i.e. withholding treatment, physician-assisted suicide euthanasia) and preferences about the focus of treatment in the last week of life (i.e. comfort care versus extending life) were examined. Written ADs were present in 14% of the sample. A quarter had designated a surrogate decision-maker. Co-morbidity and perceived self-efficacy (PSE) were positively associated with ADs. About half the sample had expressed a preference in favour or against one or more medical decisions at the end of life. Predictors positively associated with expressing a preference were co-morbidity, dying from cancer, and PSE. Being religious was negatively associated with expressing a preference. The knowledge of the proxy regarding the older person's preference for the focus of treatment was dependent on the patient's symptom burden as perceived by the proxy. The majority of older persons had died without either an AD, or having expressed preferences for end-of-life care. Stimulating the formulation of ADs may help professionals who work with older people to understand these preferences better, especially in the case of non-cancer patients and those with low PSE.

PMID: 15474202 [PubMed - in process]

86: Soc Sci Med. 2004 Aug;59(4):775-85.

Physician commitment in end of life care--perspectives from New Zealand and the Netherlands.

Mitchell K.

Department of Psychology, University of Auckland, Tamaki Campus, Private Bag 92019, Auckland, New Zealand. k.mitchell@auckland.ac.nz

A social constructionist approach is taken to analyse the accounts of experiences of doctors who have provided end of life care, comprising five Dutch doctors and six New Zealand doctors who had not provided physician-assisted

death, and five Dutch doctors who had. A core theme of 'commitment' to the patient crossed all interviews and when a request for assisted death was received this theme altered and evolved differently between the groups. All respondents reacted by exploring reasons for the request and offering palliative care. When the request persisted, those who had provided euthanasia entered into a 'contractual commitment', constructing another "vulnerable" self in the negotiations that invited the sympathy of the hearer. This evolved to 'sacrificial commitment' when the physician provided euthanasia despite negative personal psychological effects. Constructing a self who is willing to sacrifice personal comfort to relieve the suffering of another is useful in silencing criticism of actions. The two groups who had not provided euthanasia, intensified their efforts to find an alternative to assisted death in a 'pledged commitment' to the patient, constructing themselves as deeply committed to the patient in an intimate struggle to meet his/her need. While New Zealand doctors denied that euthanasia had ever been an option, some Dutch doctors evolved their commitment to 'potential sacrificial commitment', constructing an open-minded and accepting self, willing to consider euthanasia despite fears of negative personal consequences. The construction of alternative 'selves' in accounts is useful in inviting sympathy and silencing potential criticism of actions that may be construed negatively (because the patient was assisted to die, or because assistance to die was refused).

PMID: 15177834 [PubMed - indexed for MEDLINE]

87: Urol Nurs. 2004 Aug;24(4):270-4, 279; quiz 280.

Being there: the essence of end-of-life nursing care.

Forest PK.

Department of Radiation Oncology, University of Iowa Hospitals and Clinics, Iowa City, IA, USA.

Competent and compassionate end-of-life care is the right of everyone. Nursing and the health care profession are obligated to meet this need for their patients and provide crucial information and support. Continued efforts must be made to increase our knowledge about the normal dying process, symptom management, and the role of the interdisciplinary team in supporting patients in their final wishes for a "good death".

PMID: 15446377 [PubMed - in process]

1: Ann Emerg Med. 2004 Jun;43(6):787-8.

Comment on:

Ann Emerg Med. 2003 Nov;42(5):665-80.

Ann Emerg Med. 2003 Nov;42(5):681-4.

Ann Emerg Med. 2003 Nov;42(5):685-8.

The smallpox vaccine and coronary artery disease: a personal perspective.

Lammert GR.

Publication Types:

Case Reports
Comment
Letter

PMID: 15259164 [PubMed - indexed for MEDLINE]

2: Ann Emerg Med. 2004 Jun;43(6):783, 791.

Images in emergency medicine. Generalized vaccinia.

Lemery J.

Department of Emergency Medicine, New York University/Bellevue Hospital, New York, NY, USA.

Publication Types:

Case Reports

PMID: 15159712 [PubMed - indexed for MEDLINE]

3: Arch Ophthalmol. 2004 Sep;122(9):1407; author reply 1407-8.

Comment on:

Arch Ophthalmol. 2003 May;121(5):715-9.

The ocular complications of smallpox and smallpox immunization.

Smith JA, Casey CG, Tierney BC.

Publication Types:

Comment
Letter

PMID: 15364730 [PubMed - indexed for MEDLINE]

4: Clin Infect Dis. 2004 Jun 15;38(12):1749-53. Epub 2004 May 19.

Modified vaccinia Ankara: potential as an alternative smallpox vaccine.

McCurdy LH, Larkin BD, Martin JE, Graham BS.

Vaccine Research Center, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, Maryland 20892-3017, USA.

Despite the declaration of smallpox eradication in 1980, the existence of variola stockpiles and the threat of bioterrorism demand that immunity to smallpox through vaccination be maintained. Although the currently available vaccine was used for the most successful medical intervention ever accomplished,

it also is associated with side effects that are difficult to accept in a vaccine for a disease that has not been present for >25 years. Herein, we review alternative approaches to maintaining immunity to smallpox through vaccination with attenuated poxviruses, and we suggest modified vaccinia Ankara (MVA) as a leading candidate for an alternative smallpox vaccine.

PMID: 15227622 [PubMed - indexed for MEDLINE]

5: Hist Sci (Tokyo). 2004 Mar; 13(3):164-75.

Western medicine, Korean government, and imperialism in late nineteenth-century Korea: The cases of the Choson government hospital and smallpox vaccination.

Shin DW.

Korea Advanced Institute of Science and Technology, 373-1 Guseong-dong, Yuseong-gu, Daejeon 305-701, Republic of Korea.

Publication Types:

Biography

Historical Article

Personal Name as Subject:

Chi SY

Allen HN

PMID: 15212040 [PubMed - indexed for MEDLINE]

6: J Allergy Clin Immunol. 2004 Aug; 114(2):454-6.

Latex allergens are not detectable in reconstituted smallpox vaccine or vaccine vial stoppers.

Poland G, Ovsyannikova IG, Jones RT, Yunginger JW.

Publication Types:

Letter

PMID: 15341028 [PubMed - indexed for MEDLINE]

7: J Am Coll Cardiol. 2004 Jul 7; 44(1):201-5.

Incidence and follow-up of inflammatory cardiac complications after smallpox vaccination.

Eckart RE, Love SS, Atwood JE, Arness MK, Cassimatis DC, Campbell CL, Boyd SY, Murphy JG, Swerdlow DL, Collins LC, Riddle JR, Tornberg DN, Grabenstein JD, Engler RJ; Department of Defense Smallpox Vaccination Clinical Evaluation Team.

U.S. Army Medical Command, Brooke Army Medical Center, Fort Sam Houston,
Texas
78234-6200, USA. Robert.Eckart@us.army.mil

OBJECTIVES: The purpose of this study was to assess the follow-up of patients with vaccinia-associated myocarditis. **BACKGROUND:** With the threat of biological warfare, the U.S. Department of Defense resumed a program for widespread smallpox vaccinations on December 13, 2002. One-year afterwards, there has been a significant increase in the occurrence of myocarditis and pericarditis among those vaccinated. **METHODS:** Cases were identified through sentinel reporting to military headquarters, systematic surveillance, and spontaneous reports. **RESULTS:** A total of 540,824 military personnel were vaccinated with a New York City Board of Health strain of vaccinia from December 2002 through December 2003. Of these, 67 developed myopericarditis at 10.4 +/- 3.6 days after vaccination. The ST-segment elevation was noted in 57%, mean troponin on admission was 11.3 +/- 22.7 ng/dl, and peak cardiac enzymes were noted within 8 h of presentation. On follow-up of 64 patients (96%) at a mean of 32 +/- 16 weeks, all patients had objective normalization of echocardiography, electrocardiography, laboratory testing, graded exercise testing, and functional status; 8 (13%) reported atypical, non-limiting persistent chest discomfort. **CONCLUSIONS:** Post-vaccinal myopericarditis should be considered in patients with chest pain within 30 days after smallpox vaccination. Normalization of echocardiography, electrocardiography, and treadmill testing is expected, and nearly all patients have resolution of chest pain on follow-up.

Publication Types:

Review
Review, Tutorial

PMID: 15234435 [PubMed - indexed for MEDLINE]

8: J Antimicrob Chemother. 2004 Jul;54(1):1-5. Epub 2004 May 26.

Antiviral prophylaxis of smallpox.

Bray M, Roy CJ.

Biodefense Clinical Research Branch, Office of Clinical Research, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, Maryland 20892, USA. mbray@niaid.nih.gov

Proof-of-concept studies suggest that current defences against smallpox could be strengthened by supplementing vaccination with antiviral drug prophylaxis, based on aerosolized or orally available forms of the long-acting medication cidofovir. Delivery of aerosolized cidofovir to mice results in its prolonged retention in respiratory tissues and protection against lethal intranasal or aerosol poxviral challenge. Although cidofovir itself is not orally available, the addition of an alkoxyalkanol ether side-chain allows it to be absorbed from the gastrointestinal tract. This also markedly increases its antiviral activity and lengthens its intracellular half-life from roughly 3 to 8-10 days. Oral treatment also protected mice against lethal poxviral challenge. These results suggest that a single aerosol dose of cidofovir (or an alkoxyalkanol-ether derivative) could provide prolonged protection against initiation of smallpox infection, whereas oral treatment could prevent both initiation of infection and

internal dissemination of virus. Both approaches may avoid the nephrotoxicity that occasionally results from intravenous cidofovir therapy.

Publication Types:

Review

Review, Tutorial

PMID: 15163655 [PubMed - indexed for MEDLINE]

9: J Environ Health. 2004 Jun;66(10):41.

Report assesses tools for measuring smallpox readiness.

[No authors listed]

Publication Types:

News

PMID: 15216567 [PubMed - indexed for MEDLINE]

10: J Gen Intern Med. 2004 May;19(5 Pt 1):451-5.

Differential willingness to undergo smallpox vaccination among African-American and white individuals.

Micco E, Gurmankin AD, Armstrong K.

Department of Medicine, University of Pennsylvania School of Medicine,
Philadelphia, PA 19104-6021, USA. ellyn@mail.med.upenn.edu

OBJECTIVE: To examine potential disparities in willingness to be vaccinated against smallpox among different U.S. racial/ethnic groups. **DESIGN:** Cross-sectional survey using an experimental design to assess willingness to be vaccinated among African Americans compared to whites according to 2 strategies: a post-exposure "ring vaccination" method and a pre-exposure national vaccination program. **SETTING:** Philadelphia County district courthouse. **PARTICIPANTS:** Individuals awaiting jury duty. **MEASUREMENTS:** We included 2 scenarios representing these strategies in 2 otherwise identical questionnaires and randomly assigned them to participants. We compared responses by African Americans and whites. **MAIN RESULTS:** In the pre-exposure scenario, 66% of 190 participants were willing to get vaccinated against smallpox. In contrast, 84% of 200 participants were willing to get vaccinated in the post-exposure scenario ($P = .0001$). African Americans were less willing than whites to get vaccinated in the pre-exposure scenario (54% vs 77%; $P = .004$), but not in the post-exposure scenario (84% vs 88%; $P = .56$). In multivariate analyses, overall willingness to undergo vaccination was associated with vaccination strategy (odds ratio, 3.29; 95% confidence interval, 1.8 to 6.1). **CONCLUSIONS:** Racial disparity in willingness to get vaccinated varies by the characteristics of the vaccination program. Overall willingness was highest in the context of a post-exposure scenario. These results highlight the importance of considering social issues when constructing bioterror attack response plans that adequately address the needs of all of society's members.

PMID: 15109343 [PubMed - indexed for MEDLINE]

11: JAMA. 2004 Sep 8;292(10):1205-12.

Vaccination success rate and reaction profile with diluted and undiluted smallpox vaccine: a randomized controlled trial.

Talbot TR, Stapleton JT, Brady RC, Winokur PL, Bernstein DI, Germanson T, Yoder SM, Rock MT, Crowe JE Jr, Edwards KM.

Department of Medicine, Vanderbilt University School of Medicine, Nashville, TN 37232, USA.S

CONTEXT: Additional smallpox vaccine doses are needed to augment current US national stockpile. Aventis Pasteur smallpox vaccine (APSV), initially manufactured in the 1950s from the New York Board of Health vaccinia strain in a frozen preparation, appears as effective as lyophilized vaccine but the effectiveness of diluted doses of APSV is unclear. OBJECTIVE: To compare the vaccination success rate and the reaction profile of various APSV dilutions. DESIGN, SETTING, AND PARTICIPANTS: A double-blind, randomized controlled trial of 340 healthy vaccinia-naïve adults aged 18 to 32 years from 3 academic medical centers who were vaccinated with 1 of 3 strengths of APSV dilutions (undiluted, 1:5, and 1:10) between October 9, 2002, and February 24, 2003. Volunteers were followed up every 3 to 5 days until the vaccination site healed for bandage changes, vaccine response assessment, and adverse event evaluation, followed by 1- and 2-month clinic evaluations and 6-month telephone interview. MAIN OUTCOME MEASURES: Successful vaccination, defined by presence of a vesicle or pustule at the inoculation site 6 to 11 days postvaccination, and local and systemic reactions to vaccination. RESULTS: A total of 340 volunteers were vaccinated (vaccine dose: undiluted, n = 113; 1:5 dilution, n = 114; and 1:10 dilution, n = 113). Following vaccination, 99.4% (95% confidence interval [CI], 97.9%-99.9%) of all volunteers had successful vaccinations. Success rates did not differ between the dilution groups (undiluted, 100.0%; 95% CI, 96.8%-100.0%; 1:5 dilution, 98.2%; 95% CI, 93.8%-99.8%; 1:10 dilution, 100.0% 95% CI, 96.8%-100.0%; P = .33). Overall, 99.7% of volunteers reported at least 1 local symptom at the vaccination site, and 61.8% had axillary lymphadenopathy, 15.0% developed satellite lesions, and 7.6% developed a rash away from the vaccination site. Fever developed in 21.5%. No differences were noted in local or systemic reactions between the 3 dilution groups (P > .05 for each comparison). A total of 25% of volunteers missed scheduled duties due to vaccine-related symptoms. CONCLUSIONS: Even at diluted doses, APSV is an effective smallpox vaccine, allowing for expansion of the current stockpile. However, reactogenicity was not reduced with dilution of the vaccine and, as with other smallpox vaccines, may impair daily activities.

Publication Types:

Clinical Trial

Multicenter Study

Randomized Controlled Trial

PMID: 15353533 [PubMed - indexed for MEDLINE]

12: Mayo Clin Proc. 2004 Sep; 79(9):1193-6.

Stevens-Johnson syndrome after immunization with smallpox, anthrax, and tetanus vaccines.

Chopra A, Drage LA, Hanson EM, Touchet NL.

Department of Internal Medicine, Mayo Clinic College of Medicine, Rochester, Minn 55905, USA.

A 19-year-old male military recruit developed erythema multiforme 20 days after receiving a triad of vaccinations: smallpox (vaccinia virus), anthrax, and tetanus. Over the course of a few days, the erythema multiforme evolved into Stevens-Johnson syndrome, associated with widespread bullae, stomatitis, conjunctivitis, and fever. After 7 days of conservative management, the patient's signs and symptoms improved. This case serves as a timely reminder of a severe and potentially life-threatening complication of smallpox vaccination.

Publication Types:
Case Reports

PMID: 15357044 [PubMed - indexed for MEDLINE]

13: Med Hist. 2004 Apr; 48(2):199-228.

Variolation, vaccination and popular resistance in early colonial south India.

Brimnes N.

Department of History, Aarhus University, DK-8000 Aarhus C, Denmark.

Publication Types:
Historical Article

PMID: 15151104 [PubMed - indexed for MEDLINE]

14: Minn Med. 2004 May; 87(5):34-9.

Smallpox in Saint Paul and Minneapolis, 1924-1925.

Nelson PD.

Publication Types:
Historical Article

PMID: 15191066 [PubMed - indexed for MEDLINE]